http://researchspace.auckland.ac.nz

ResearchSpace@Auckland

Copyright Statement

The digital copy of this thesis is protected by the Copyright Act 1994 (New Zealand).

This thesis may be consulted by you, provided you comply with the provisions of the Act and the following conditions of use:

- Any use you make of these documents or images must be for research or private study purposes only, and you may not make them available to any other person.
- Authors control the copyright of their thesis. You will recognise the author's right to be identified as the author of this thesis, and due acknowledgement will be made to the author where appropriate.
- You will obtain the author's permission before publishing any material from their thesis.

To request permissions please use the Feedback form on our webpage.
http://researchspace.auckland.ac.nz/feedback

General copyright and disclaimer

In addition to the above conditions, authors give their consent for the digital copy of their work to be used subject to the conditions specified on the Library Thesis Consent Form and Deposit Licence.
Adolescent Siblings of Cancer Survivors

Eleanor Riddick

A thesis submitted in partial fulfilment of the requirements of the degree of
DEDICATION

This thesis is dedicated to all the young people in New Zealand who have a sister or brother with cancer. In particular, the participants in this study, whose honesty and willingness to share aspects of their life with me made this research possible.
Acknowledgements

This thesis was initially dreamed up while volunteering with Camp Quality. I was taking a break with a few other volunteers and we were talking about what life must be like for the siblings of the campers we knew. Someone wondered aloud if there was any research on this, and we all agreed that if there wasn’t, there should be. At this point people started looking at me and someone said “Ele, aren’t you starting your Doctorate in Psychology? Why don’t you study this?” At first I dismissed the idea; I’d already decided on a project and I’d spent the last month reading up on something else altogether. But the idea wouldn’t leave my head, and by the time camp was over, I was itching to get into the databases and find out what had already been done. Within 24 hours I had crafted a convincing (pleading) email to my existing supervisor, asking if she would still support and supervise me if I changed projects to do something neither of us had any experience in, but which I was suddenly passionate about.

I am so grateful she said yes. Doing a project in an unknown field is difficult. But when you spend three and a half years thinking and talking about one topic, it helps if it’s a topic you feel passionate about, which people are interested in hearing about, and where you can see how it will make a difference.

The most important person involved in pulling this thesis together has been my supervisor Elizabeth Peterson. Liz has guided me, pushed me, and left me alone, depending on what I’ve needed at different times. Her dedication and commitment has far exceeded my expectations of any supervisor. My secondary supervisors Claire Cartwright and John Read have also been extremely helpful.

Second is the participants themselves, and the agencies that helped me recruit them: Child Cancer Foundation, Camp Quality, and CanTeen, thank you for your help. It was such a privilege to meet my interview participants in person, I really enjoyed it, and I was so impressed with your willingness to discuss the really sensitive, difficult topics with me.

Thank you to my flatmates, especially the Taylor’s road beauties, for creating a flat that felt like a home. Thank you to my classmates, who from the first day of the clinical program have been unfailingly loving and supportive. Thank you to my cell groups, who’ve prayed dozens of prayers for my thesis progress. Thank you to my family for listening to me rant about the thesis, and to my siblings, for teaching me how important siblings are! And thank you to the Doars, for treating me like a second daughter when my family was far away.

Finally, all my close friends: Going through the clinical program and writing this thesis taught me a lot about being willing to ask for help when I need it. You’ve all taught me that you’re there for me when I need you. You’ve cooked for me, brought me flowers and chocolate and wine and trashy novels. You’ve dragged me out of the office when I’ve needed a break, hustled me back into the office when I’ve been procrastinating, and you’ve proofread my work. You’ve distracted me with wonderfully scandalous emails, housed me when I was a little bit homeless, and put up with me cancelling plans or being unreliable. I’ve learned a lot about friendship in the past four years and I’m so grateful to all of you.
Abstract

This thesis reports on the psychological adjustment of adolescent siblings of cancer survivors in New Zealand. In contrast to most previous research which is concentrated on the first two to four years following diagnosis, this study focuses on the time following discharge off treatment. This thesis reports on two studies, a quantitative questionnaire study ($N = 31$), and a qualitative interview study ($N = 10$).

The first study was quantitative and explored the impact of different family dynamics and coping strategies on three main psychological adjustment outcomes: depression, self-esteem and wellbeing. Participants were aged 12 to 18, predominantly female ($N = 20$), and their siblings had completed treatment between three months ago and 16 years ago. Findings from the questionnaire study indicated that depression scores in the CES-DC scale were above the cut-off score for depression for 76% of this sample. Regression analysis suggested that increased depression was significantly predicted by lower optimism, being alienated by peers, smaller family size, and by unfair parental differential treatment when parents were perceived as being relatively more affectionate and more controlling of the child who had cancer. Higher self-esteem was predicted by higher optimism. Wellbeing was highest when participants were optimistic and when their relationship with their sibling was low in warmth.

The second study reports the findings of semi-structured interviews with 10 siblings who had participated in study one. Thematic analysis identified six themes related to their experience of having a sibling who had cancer. These themes were named: stress and distress; I wasn’t anyone’s priority; coping; feeling involved; it’s not all negative; and connection and disconnection. These themes helped give a rich context to some of the quantitative findings in study one.

Overall the findings suggest that adolescent siblings of cancer survivors in New Zealand may be at risk of developing problems with low mood. Promoting optimism may be an important part of supporting positive adjustment in siblings. In addition, the various relationships siblings hold, within and outside the family seem to be important for predicting psychological adjustment. The implications of these findings for siblings, their family members, and professionals working with their families are briefly discussed.
# ABSTRACT

# CHAPTER ONE: INTRODUCTION

## Child Cancer in New Zealand

## Sibling Relationships

## Siblings of Children with Cancer

- Individual effects
- Factors that may impact on sibling adjustment
- The present study

# CHAPTER TWO: METHOD FOR THE QUESTIONNAIRE STUDY

## Participants

## Materials

- Depression: Centre of Epidemiological Studies, Depression, Children version (CES-DC) (Weissman, Orvaschel, & Padian, 1980)
- Rosenberg self-esteem scale (RSE) (Rosenberg, 1965)
- Psychological Well-being Scale, short form (Ryff & Keyes, 1995)
- Life orientation test (LOT) (Scheier & Carver, 1985)
- Sibling inventory of differential experience (SIDE) (Daniels & Plomin, 1985b)
- Perceived fairness of differential treatment (Kowal et al., 2002)
- Sibling relationship questionnaire (SRQ) (Furman, 1988)
- Inventory of parent and peer attachment, peer attachment subscale (IPPA) (Armsden & Greenberg, 1987)

## Procedure

- Data collection
- Analysis plan

# CHAPTER THREE: RESULTS FROM THE QUESTIONNAIRE STUDY

## Missing data

## Tests of assumptions for parametric testing

## Reliability
<table>
<thead>
<tr>
<th>Chapter</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Descriptives</td>
<td></td>
<td>59</td>
</tr>
<tr>
<td>Psychosocial adjustment</td>
<td></td>
<td>59</td>
</tr>
<tr>
<td>Optimism</td>
<td></td>
<td>61</td>
</tr>
<tr>
<td>Parental differential treatment</td>
<td></td>
<td>61</td>
</tr>
<tr>
<td>Sibling relationships</td>
<td></td>
<td>62</td>
</tr>
<tr>
<td>Peer relationships</td>
<td></td>
<td>62</td>
</tr>
<tr>
<td>Correlations</td>
<td></td>
<td>62</td>
</tr>
<tr>
<td>Regressions analysis</td>
<td></td>
<td>65</td>
</tr>
<tr>
<td>Predicting psychosocial adjustment from demographic variables</td>
<td></td>
<td>66</td>
</tr>
<tr>
<td>Predicting psychosocial adjustment from grouped variables</td>
<td></td>
<td>67</td>
</tr>
<tr>
<td>Predicting outcome variables from grouped variables with optimism as a fixed predictor</td>
<td></td>
<td>69</td>
</tr>
<tr>
<td>Questionnaire study summary</td>
<td></td>
<td>73</td>
</tr>
</tbody>
</table>

**CHAPTER FOUR: METHOD AND RESULTS OF THE INTERVIEW STUDY**.. 74

<table>
<thead>
<tr>
<th>Section</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interviews</td>
<td></td>
<td>75</td>
</tr>
<tr>
<td>Thematic analysis</td>
<td></td>
<td>76</td>
</tr>
<tr>
<td>Personal disclosure statement</td>
<td></td>
<td>78</td>
</tr>
<tr>
<td>Interview study results</td>
<td></td>
<td>79</td>
</tr>
<tr>
<td>Themes</td>
<td></td>
<td>79</td>
</tr>
<tr>
<td>Subthemes</td>
<td></td>
<td>79</td>
</tr>
<tr>
<td>Stress and distress</td>
<td></td>
<td>80</td>
</tr>
<tr>
<td>I wasn’t anyone’s priority</td>
<td></td>
<td>82</td>
</tr>
<tr>
<td>Coping</td>
<td></td>
<td>85</td>
</tr>
<tr>
<td>Feeling involved</td>
<td></td>
<td>90</td>
</tr>
<tr>
<td>It’s not all negative</td>
<td></td>
<td>92</td>
</tr>
<tr>
<td>Connection and disconnection</td>
<td></td>
<td>95</td>
</tr>
<tr>
<td>Summary of the interview study</td>
<td></td>
<td>98</td>
</tr>
</tbody>
</table>

**CHAPTER FIVE: DISCUSSION**................................................................. 99

<table>
<thead>
<tr>
<th>Section</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychological adjustment</td>
<td></td>
<td>100</td>
</tr>
<tr>
<td>Family size</td>
<td></td>
<td>103</td>
</tr>
<tr>
<td>Topic</td>
<td>Page</td>
<td></td>
</tr>
<tr>
<td>--------------------------------------------</td>
<td>------</td>
<td></td>
</tr>
<tr>
<td>Optimism</td>
<td>105</td>
<td></td>
</tr>
<tr>
<td>Parental differential treatment</td>
<td>108</td>
<td></td>
</tr>
<tr>
<td>Peer relationships</td>
<td>109</td>
<td></td>
</tr>
<tr>
<td>Sibling warmth</td>
<td>111</td>
<td></td>
</tr>
<tr>
<td>Strengths and Limitations</td>
<td>114</td>
<td></td>
</tr>
<tr>
<td>Implications</td>
<td>116</td>
<td></td>
</tr>
<tr>
<td>Future research</td>
<td>118</td>
<td></td>
</tr>
</tbody>
</table>

**CHAPTER SIX: CONCLUSIONS** ................................................................. 120

**APPENDICES** ......................................................................................... 133

**APPENDIX A** ......................................................................................... 134

**APPENDIX B** ......................................................................................... 136

**APPENDIX C** ......................................................................................... 148

**APPENDIX D** ......................................................................................... 155

**APPENDIX E** ......................................................................................... 159

**APPENDIX F** ......................................................................................... 160

**APPENDIX G** ......................................................................................... 165
Chapter One: Introduction

Chapter overview.

This study examines certain aspects of the lives of adolescents who have a brother or sister who has successfully completed treatment for cancer. It begins by giving a brief overview of childhood cancer and its prevalence and management in New Zealand. Following this, the research on siblings of children with cancer and the factors relating to their adjustment will be outlined. In particular, the influence of personal circumstances, coping styles, family, and peer factors on sibling adjustment will be explored. Finally, the aim of the current study will be described along with how it attempts to address gaps in the existing literature base.

Throughout the document, a child that is on treatment or recently diagnosed with cancer will be referred to as ‘the patient’ to differentiate them from other family members. Children who have finished cancer treatment and are in remission will be called ‘survivors’. Throughout the study, the focus child, who is a brother or sister of the patient/survivor will be referred to as the ‘sibling’. This is consistent with previously published articles among this population and is used for easy identification, our intention is not to give a label which defines them only in relation to another (the patient/survivor) but to facilitate easy communication.

Child Cancer in New Zealand

Cancer is a complex illness with many different manifestations, and consequently many treatments. Every patient, and therefore every sibling of a cancer patient, will be exposed to a different journey towards wellness. To understand some of the breadth of experiences these survivors and siblings have faced, the following section will briefly describe what cancer is, how prevalent it is, the risks it presents, and how it is treated and managed in New Zealand. Secondly, as this study particularly focuses on siblings of cancer survivors, results from research assessing some of the possible long-term effects of cancer and cancer treatment will be mentioned.

The term ‘cancer’ describes a number of diseases, which affect a number of different organs, in different ways. Cancer usually originates from a single cell, with a mutated DNA. As a result of this mutation, the cell divides without restrain from the body’s usual controls. The resulting ‘neoplasm’ (literally, ‘new growth’) is considered cancerous or malignant if the cells
invade and destroy nearby tissue, or if they spread to other parts of the body (Waring, 2001). Each different cancer has a different cause, features, treatments, and prognosis (Di-Gallo, 2006; J. M. Patterson, Holm, & Gurney, 2004). Cancers can be particularly lethal compared to other childhood diseases (Drotar, 2006), in New Zealand, neoplasms were the most common cause of death from medical causes for 5-19 year olds in the period from 2003 to 2008 (Mishra, Maudgal, Theunissen, & Rieffe, 2012).

The New Zealand cancer registry (NZCR) collects information on all diagnoses of cancer in New Zealand. In 2009, the latest year for which information is available, there were 117 new registrations of cancer for people aged 0-14 (76-male, 41 female), representing 11.1 to 16.0 per 100,000 population depending on the specific age range (Ministry of Health, 2012). In the same year there were 20 deaths from cancer in 0-14 year olds (9 male, 11 female) (Ministry of Health, 2012). These mortality rates correspond to a five-year survival ratio of .803 for children aged 0-14 for the 2008 - 2009 period (Health., 2012). This is consistent with overseas rates (Alderfer et al., 2009). Consequently, each year, there are approximately 160 new child/adolescent-cancer survivors, many of whom will have siblings.

In New Zealand, there are currently only two paediatric oncology treatment centres: Starship Children’s hospital in Auckland, and Christchurch hospital in Christchurch. This is reduced from five in 1995 meaning many more families do not have local access to the services they require and families must travel. The long distances mean siblings are often isolated from the day to day rituals of treatment as they stay in their home-town during their sibling’s extended hospital stays.

Treatment type and duration depends on the individual situation. Common treatments are surgery, chemotherapy, radiation therapy, and bone marrow or stem-cell transplants (Dixon-Woods, Young, & Heney, 2005), these treatments will often be combined in complimentary ways (Waring, 2001). Treatment for cancer is a painful process (Drotar, 2006; J. M. Patterson et al., 2004), and has severe side-effects including loss of hair, lowered immune system, and difficulty eating (Chardas, 2005). Depending on the cancer, treatment may continue for years (Dixon-Woods et al., 2005; Dobson, 2007), with continual and periodic disruption to the family throughout this time (Di-Gallo, 2006).

Cancer is a severe illness that impacts upon all family members. Sibling’s lives are often changed dramatically when their sibling is on treatment, although the level of involvement and
change siblings experience in relation to the patient’s cancer will vary considerably from family to family. Previous qualitative research has identified certain aspects of cancer which siblings find particularly difficult. These include fear about their sibling’s death (Nolbris, Enskar, & Hellstrom, 2007), seeing their sibling in pain (Woodgate, 2006), and seeing visible changes (hair-loss, weight change etc.) in their sibling (Nolbris et al., 2007; Woodgate, 2006). These experiences increase feelings of helplessness in the sibling, and highlight the severity of the illness (Nolbris et al., 2007; Woodgate, 2006). In relation to the psychological impact of cancer, siblings are the least researched immediate family member (Alderfer et al., 2009). Research examining the experiences of siblings of children with cancer will help families and practitioners working with families to understand some of the widespread impact of cancer and possibly help them prepare for aspects of the cancer journey they may not have anticipated.

Children are considered ‘cured’ after five years off-treatment in remission, however, the complete absence of cancerous cells cannot be confirmed, and, survivors are always at higher risk than the general population for developing a subsequent cancer (Di-Gallo, 2006; O’Brien & Tomlinson, 2005). Knowing this risk can contribute to anxiety problems for survivors and their family members (Rourke & Kazak, 2005).

Furthermore, aside from the risk of relapse, many child-cancer survivors will have on-going ‘late effects’ (Dixon-Woods et al., 2005). Late effects include medical, psychological, and social problems occurring as a result of cancer, or cancer treatment. These effects may be known from the moment treatment ends, or not become apparent until many years later. The Child Cancer Survivor study in the US found 75% of survivors had chronic health problems: 30 years after finishing treatment; they were eight times more likely than their siblings to have chronic health problems (Oeffinger et al., 2006). In the UK, 58% of survivors had at least one chronic medical problem, many had two or more problems (Dixon-Woods et al., 2005). Many individuals and families expect life to resume its former qualities as soon as the cancer is in remission and treatment ends (Di-Gallo, 2006; Rourke & Kazak, 2005), and may be surprised and disappointed when cancer continues to be a feature of their life (Faulkner, Peace, & O’Keeffe, 1995). As cancer continues to effect patients long after treatment has ended, so it may continue to affect the family and siblings. However, most research with siblings has been limited to a period relatively close to the time of treatment, such as the first two to four years.
In addition to medical late-effects, psychosocial adjustment of child-cancer survivors has been a subject of investigation. A local New Zealand study has recently been completed assessing the psychosocial adjustment of 170, 12-18 year old child-cancer survivors (at least two years post-treatment) (Yallop, 2011). When compared to a reference group of New Zealand adolescents, these child-cancer survivors reported greater psychosocial wellbeing (measured on the World Health Organisation (Five) Wellbeing Index (WHO-5)), and a non-significant trend towards less depression (measured with the Reynolds Adolescent Depression Scale - short form (RADS2-SF). Although an important minority still reported some difficulties with depression, anxiety and wellbeing, as a group, child-cancer survivors were equally as well adjusted, if not better adjusted than their peers (Yallop, 2011). However, as with many studies of this population and the sibling population, this study only considered factors such as demographics and cancer/treatment characteristics to understand the variations and trends in psychosocial adjustment occurring in the group. Factors which are known to relate to general adolescent wellbeing such as social connection, self-esteem and functional family relationships (Carr, 2006) were not considered in this population.

When cancer occurs in a child or young person, the time of diagnosis is an especially difficult time for everybody in the family as they encounter feelings of shock, fear, anger, helplessness and guilt (Drotar, 2006; Sidhu, Passmore, & Baker, 2005). There is barely any time for adjustment as treatment typically begins immediately. This precipitates a sudden transition in the family member’s roles, priorities, and routines with no preparation (McCubbin, Balling, Possin, Frierdich, & Bryne, 2002). A diagnosis of cancer in a child affects not only the patient, but the whole family (Nolbris et al., 2007). During this time, families struggle to meet the needs of all members as the needs of the sick child conflict with the needs of siblings, financial responsibilities, education, and maintaining a home (Di-Gallo, 2006). Because of the long-term nature of cancer treatment, other priorities cannot be entirely put aside until the sickness is resolved (J. M. Patterson et al., 2004). Siblings must continue with their education, and financial obligations typically mean at least one parent remains working (Dixon-Woods et al., 2005). When the treatment centre is a long distance from the family home, such as often occurs in New Zealand, the disruption to the family and siblings may be even more pronounced. Relationships within the family are forced to adapt as physical locations separate people, and roles and
responsibilities of each family member change (McCubbin et al., 2002). These changes in relationships, particularly as they relate to the well siblings, have not been examined in depth.

In identity formation, people often identify themselves in relation to relationships with other people, as well as groups they belong to, and events they have experienced. Survivorship has been examined as central concept to the identity of many cancer survivors (Dixon-Woods et al., 2005). However, the importance of their experience with cancer for siblings’ long-term self-identification has not been established. Questions of how central ‘cancer’ becomes to their life and their identity long-term have not been addressed. Furthermore, having faced the risk of losing a brother or sister, these siblings may understand the role of ‘being a sibling’ differently to others (Nolbris et al., 2007). Their report of the sibling relationship and the centrality of this relationship in their identity may differ from other populations who have not had to consider a real possibility of a sibling’s death.

**Sibling Relationships**

People who have siblings often report that the sibling relationship is a central relationship in their lives. However, this relationship has been the subject of far fewer studies than most other long-term relationships. This is apparent both in terms of the general population, and specific populations such as in families where a child has had cancer (Stoneman, 2005). This section briefly presents what is known and not known about sibling relationships in the general population. Research specifically relating to siblings of children with cancer will be discussed in the following section.

In New Zealand, the 2001 census showed that 84% of children in New Zealand live in a family with other children (Smillie, 2002), 2006 census reports did not comment on the numbers of children in households and 2013 census data has not yet been released. For most children, the sibling subsystem is the first peer group (Caffaro & Conn-Caffaro, 2003). It is a place of close to equal status (Sanders, 2004; Seligman & Darling, 2007), and is a unique relationship given its involuntary nature and the intensity occurring as a result of close proximity (Nolbris et al., 2007). The sibling relationship is for most people the longest lasting relationship of their lives (Noller, 2005). Furthermore, issues related to sibling dynamics and differences often arise in psychological therapy (Caffaro & Conn-Caffaro, 2003).
Despite the significance of the sibling relationship in people’s lives, most research on family relationships has focused on the parental relationship, and the parents’ spousal relationship. The sibling relationship has been relatively neglected (Brody, Stoneman, & McCoy, 1994; Noller, 2005; Sanders, 2004).

When the sibling relationship is examined in children and young people, two independently varying dimensions consistently emerge. These dimensions are conflict/rivalry and warmth/affection. A sibling relationship can be high in both of these qualities, one of them, or neither (Furman & Buhrmester, 1985; McHale, Kim, & Whiteman, 2006). Note that some studies have also included relative status/power and have separated conflict from rivalry (Furman & Buhrmester, 1985) and intimacy from warmth (McGuire, McHale, & Updegraff, 1996).

Satisfaction with the sibling relationship has been found to co-vary with different styles of sibling interaction (McGuire et al., 1996). In one study of sibling relationships reported by 10-11 year old first-born children \( N = 91 \) the highest satisfaction ratings were from sibling relationships high in warmth, regardless of conflict levels, followed by relationships low in both warmth and hostility, and children were least satisfied with relationships low in warmth and high in conflict (McGuire et al., 1996). Internalizing and externalising behaviours have been significantly predicted by both positive and negative affect in the sibling relationship (Buist, Deković, & Gerris, 2011; Buist, Deković, & Prinzie, 2013), and depression has been significantly predicted by sibling conflict for boys and girls, and by sibling conflict and sibling intimacy for girls (Kim, McHale, Crouter, & Osgood, 2007).

**Siblings of Children with Cancer**

Within the field of sibling research, the study of siblings of children with disabilities and illness has received a lot of attention (Noller, 2005). The present study fits within this broad paradigm, focusing specifically on adolescent siblings of child-cancer survivors in New Zealand. There has only been one previous study in New Zealand which has examined siblings of children with cancer. This study, a Master’s thesis, interviewed 37 siblings aged 7-15 years from the North Island of New Zealand, within 18-months of their sibling being diagnosed with cancer (Dobson, 2007). Findings were not published. Most previous research with siblings of children with cancer (and other disabilities) tends to take a deficit approach, investigating how the non-disabled or well siblings may have been harmed or damaged by their sibling’s illness (Cuskelly,
In contrast, the present study will examine both positive and negative aspects of psychological adjustment in siblings of children with cancer. In ‘The Encyclopedia of Positive Psychology’, ‘Psychological adjustment’ encapsulates four dimensions:

1) *psychological adjustment as the absence of psychological symptoms* (e.g., depression, anxiety);
2) *psychological adjustment as normality, or the condition of the majority*;
3) *measures of well-being as indicators of positive adjustment* (e.g., self-esteem, life satisfaction); and
4) *psychological adjustment as an individual's characteristic level of positive adaptation* (e.g., resilience, emotional intelligence). (Seaton, 2009)

The following sections will discuss the research with siblings of children with cancer, particularly as it relates to psychological adjustment. Firstly, overall findings regarding psychological adjustment of siblings will be discussed. Following this, the various circumstances and dynamics that may have an impact the psychological adjustment of siblings will be discussed with a summary of the available research on those topics.

**Individual effects.**

Many studies of siblings of children with cancer have investigated various aspects of psychological adjustment in this population. This summary of findings regarding psychological adjustment of siblings of children with cancer is divided into research assessing markers of negative psychological adjustment (such as depression, anxiety, aggression and behaviour problems) and research assessing markers of positive psychological adjustment (such as self-esteem, resilience, quality of life, wellbeing and maturity).

**Negative adjustment.**

In 2009 Alderfer et al. published a systematic review of 65 papers published in English between 1997 and 2008 concerning siblings of children with cancer. Included studies came from many different countries, representing a variety of cultures, socio-economic groups, and health systems, although 60% of studies came from North America (Alderfer et al., 2009). One of the main findings presented in this review were that quantitative studies analysing group means for
depression, anxiety, and behavioural problems typically did not find differences between siblings and norms or controls (e.g. Dolgin et al., 1997; Labay & Walco, 2004; Lahteenmaki, Sjoblom, Korhonen, & Salmi, 2004; Van Dongen-Melman, De Groot, Hählen, & Verhulst, 1995). However, when rates of siblings in clinical ranges were examined, rather than group means, rates of siblings in the clinical range where often (but not always) significantly higher than norms or controls (e.g. Houtzager, Oort, et al., 2004; Sahler et al., 1994; Sidhu, Passmore, & Baker, 2006), (Alderfer et al., 2009). This suggests that although most siblings are well adjusted, an important subset of siblings may suffer with depression, anxiety, or other psychological problems. Very little is understood about why some siblings might have more difficulties than others (this will be discussed more below in the section titled ‘Factors that may impact on sibling adjustment’). Qualitative studies may help shed some light onto how siblings feel they have been impacted by their sibling’s cancer, to better interpret the findings from quantitative studies.

A review of qualitative research with siblings of children with cancer found that a common theme across various qualitative studies was that siblings reported intense feelings: of sadness, loneliness, rejection, anxiety, anger, jealousy and guilt (Wilkins & Woodgate, 2005). It seems that although quantitative methods have not always been able to pick up on psychological problems, these siblings regularly experience emotional distress. As an example, a qualitative study in Canada analysed information from 30 siblings aged 6-21 (mean 12) using interviews, participant observation and a focus group (Woodgate, 2006). Their brothers and sisters were at various different stages of the illness. This study identified ‘enduring sadness’ as a core theme and described it as follows:

all the siblings in this study, regardless of the stage of cancer trajectory that their brother or sister was in, expressed a sense of sadness about the whole experience. Although other emotions, such as jealousy, fear, worry, anger, and guilt were experiences by the siblings, one could clearly sum up their experience with cancer as a story of sadness. ... Feelings of sadness were reported by siblings even after their brother or sister had been successfully treated for cancer, it was as if the sadness had become a part of the sibling’s persona or that the sadness had become and enduring part of their lives. (Woodgate, 2006, pp. 411)

Another common finding in qualitative studies of siblings of children with cancer is that many siblings struggle with conflicting feelings around their brother or sister’s cancer. On one
hand, they want the best for their sibling, on the other hand, they feel neglected and sorry about the experiences they are having as a sibling. This leads to guilt over feeling selfish, and a perception that they have no right to feel that they are suffering, because their experience is minimal in comparison to the patient’s suffering (Dixon-Woods et al., 2005; Wilkins & Woodgate, 2005; Woodgate, 2006).

One potentially influential factor that has only been minimally explored may be the country of investigation (see Dolgin et al., 1997 for an exception). Every country has different health systems, different cultures, and different support services for child cancer which may influence adaptation of siblings. In the systematic review, one half of the studies on this topic came from the United States (Alderfer et al., 2009). But in considering other countries, a longitudinal study in the Netherlands examined siblings’ psychological adjustment at one month, six months, 12 months and 24 months after their brother or sister’s diagnosis with cancer (Houtzager, Grootenhuis, Caron, & Last, 2004; Houtzager, Grootenhuis, Hoekstra-Weebers, & Last, 2005; Houtzager, Oort, et al., 2004). Their findings indicated that overall, there was some distress in the first four to eight weeks after diagnosis, but six-months after diagnosis participants’ mean scores on measures of anxiety, and self and parent reported behavioural and emotional problems indicated adjustment the same as, or better than a normative reference group (Houtzager, Oort, et al., 2004). In contrast, when the experiences of 8-15 year old siblings of children diagnosed with cancer in the past 18 months (mean nine months) in New Zealand were studied, mean sibling anxiety and mean depression were significantly higher than comparative groups (Dobson, 2007). This is a concerning finding because it suggests that siblings in New Zealand may have a significantly different experience to their overseas counterparts leading to much poorer outcomes. Further investigation is necessary to see if Dobson’s results are replicated, and to determine how siblings in New Zealand could be supported more effectively so they do not suffer problematic depression and anxiety.

In conclusion, findings regarding the psychological adjustment of siblings are mixed. Most quantitative studies from around the world suggest most siblings as a group do not differ from norms or controls on measures of adjustment. Yet reports of intense emotions and enduring sadness are a recurrent theme across many different qualitative studies and rates of siblings in clinical ranges of measures of psychopathology may be high. Furthermore, the psychological adjustment of siblings may differ depending on the country under investigation. So far, the very
limited research of siblings in New Zealand suggests these siblings may have significantly more problems with psychological adjustment than siblings in other parts of the world. It is therefore very important to research siblings in New Zealand to improve our understanding of how they may be similar and different to siblings studied in other countries.

Positive adjustment.

A number of studies have found positive outcomes from the experience of having a sibling with cancer. The ‘deficit’ approach to research in psychology means these positive aspects of adjustment have not been as extensively investigated as negative aspects of adjustment (Stoneman, 2005). However, a number of qualitative studies with siblings of children with cancer and their parents (reporting on siblings) have themes relating to gains such as: confidence, maturity, self-esteem, and empathy (Barbarin et al., 1995; Sloper, 2000; Wilkins & Woodgate, 2005) and there are some studies which have investigated self-esteem and self-concept quantitatively in siblings (Murray, 2001; Packman et al., 2004; Sidhu et al., 2006). The paragraphs below will outline the mechanisms by which these changes are thought to occur, and outline studies reporting on positive gains through cancer.

Qualitative research has tended to combine positive consequences of sibling cancer such as improved self-esteem, increased independence, responsibility, and maturity, and increased compassion or empathy into broad themes such as ‘gains’ (Sloper, 2000) or ‘impact of the illness’ (Chesler, Allswede, & Barbarin, 1992). One qualitative longitudinal study in the United Kingdom conducted semi-structured interviews with 94 siblings aged 8-16 at five to ten months post diagnosis (mean 6.6), then again 9-15 months later (mean 12.4) (Sloper, 2000). At the first time point, 20% of participants reported increased maturity or compassion, but by time two this had risen to almost 50% (Sloper, 2000). Another study in the United States interviewed 21 young people aged 10-21 whose siblings were either ‘living with’ cancer or had died from cancer (Chesler et al., 1992). One questions asked how they thought they were different because of their sibling’s cancer. While many younger participants reportedly said they had not changed, older participants were more likely to note improved resilience, and maturity (Chesler et al., 1992). Finally, one large scale study in the United States (Sargent et al., 1995) used a structured interview technique to interview 254 siblings from 179 families with a child diagnosed 6-42 months prior to recruitment. Siblings were aged 5-18 (mean 10.65) at the time of interviewing.
For the question “What do you see as the biggest change that has happened to you since your brother/sister was diagnosed with cancer?” the most common response type was grouped under the heading “became more compassionate and caring”, representing 16% of the sample. A further 6% said they “became more mature”. Both of these were more often reported by older participants than younger participants (Sargent et al., 1995). Finally, Dobson’s study of New Zealand siblings used a benefit finding measure to assess benefits perceived as coming through the cancer experience by 8-15 year old siblings of children diagnosed in the past 24 months (Dobson, 2007). All participants reported some benefit arising from having a brother or sister with cancer on this scale which was scored from ‘not at all’ (0) to ‘extremely’ (4). The most often endorsed items were “it made me want to help others with a brother or sister with cancer” and “it taught me life is a gift” which both had mean responses of 3.00 (Dobson, 2007).

Not only siblings themselves, but their parents report these increases. Parents of the siblings in the Sargent et al. (1995) study (described above) were interviewed and results published in a different article. Over half of the sample (56%) said the sibling had become more independent, supportive and/or mature since the diagnosis of cancer in their sibling (Barbarin et al., 1995). Similarly, in a quantitative study assessing behaviour changes in 9-18 year old siblings of children on treatment ($N = 21$) in the United States (Heffernan & Zanelli, 1997), mothers completed a measure of sibling behavioural change which utilised a yes/no response format. Nearly half (47.6%) of mothers reported that siblings had increased in their sensitivity to others since their other child was diagnosed with cancer (Heffernan & Zanelli, 1997). This was based on a single item response which may not be reliable.

Most of the studies which have assessed self-esteem and self-concept using standardised measures have measured this relative to a camp program (Murray, 2001; Packman et al., 2004; Sidhu et al., 2006) with all reporting improvements in self-esteem following participation in the camp program. One of these studies was completed in the United States. The article reported participant means, but gave no further detail about how the self-concept scores of the participants compared to a general population (Murray, 2001). A second study, also from the United States utilised a pre-post design with 100 siblings (reduced to 77 at post-test) aged 6-17 years (mean 11.7) (Packman et al., 2004). They did not report the time passed since diagnosis, or the treatment-status of the patient, although 18 participants had siblings who had died. This study found that average self-esteem improved from 1.91 (four to eight weeks prior to camp) to 1.34
(12-16 weeks after camp). They report that a score of 2 indicates medium self-esteem and 0-1 indicates high self-esteem, so it appears that even prior to the intervention, these participants had moderate to high self-esteem (Packman et al., 2004). The final study, in Australia (Sidhu et al., 2006), reported at pre-test that although 40% of the sample was in the ‘clinical’ or ‘at risk’ groupings on a scale measuring emotional disturbance, self-esteem overall scores were actually slightly higher than norms, although similar to previous studies in Australia. In this study, self-esteem and self-concept did not improve significantly immediately post-camp, but at 8-weeks post-camp there was a significant improvement (Sidhu et al., 2006). Research on self-esteem and other positive gains in siblings of children with cancer is very limited and inconclusive so far (Alderfer et al., 2009).

Increases in maturity, independence, compassion and self-esteem are hypothesised to result from various experiences which may be common among siblings of children with cancer. Firstly, the unavailability of parents means they learn to take care of themselves (and often others, such as younger siblings) at a younger age than they normally would (Sloper, 2000). Secondly, they are exposed to life events that exceed the life-experiences of many far older people (Sidhu et al., 2005). Thirdly, depending on their age, cancer violates their assumption that parents can fix any problem (Sidhu et al., 2005). These circumstances contribute to an environment in which siblings develop adaptive skills to help them cope with their experience. These skills are generalisable to other environments in which independence, maturity and compassion are also adaptive.

**Factors that may impact on sibling adjustment.**

Various studies propose a multitude of different mechanisms to explain why some siblings of children with cancer display more problems with psychological adjustment than others. However, many of these have not been investigated closely. Many studies have limited their analysis of influential factors to demographic and disease related variables (Alderfer et al., 2009). In their meta-analysis, Alderfer et al. commented that an appropriate focus for future research was investigating potential moderators of adjustment such as age, and gender, but also aspects of family functioning and other broader aspects of the experience which may influence sibling adjustment (Alderfer et al., 2009).
This section of the literature review will discuss a number of aspects of the lives of siblings of children with cancer. Discussion will focus on how these may relate to psychological adjustment and where relevant, positive personal growth in this population. This section starts with ‘personal circumstances’ which discusses the situational experiences of siblings, including age, disease factors, parental mental health and other correlates related to their situation over which siblings have minimal control. The second section is ‘individual coping style’; this discusses the siblings’ techniques for dealing with their brother or sisters cancer, and how this may influence adjustment and adaptation. The third section: ‘parental differential treatment’ discusses how perceived differences in parents’ treatment of the focus sibling, in comparison to the child with cancer may influence siblings’ psychological adjustment. The fourth and fifth sections examine sibling relationships and peer relationships respectively, and how variations in these relationships may relate to psychological adjustment. The final section ‘professional intervention’ discusses the role of professionals and charities in supporting siblings, and what is known about the effect of interventions on sibling psychological adjustment. Some of these topics have not previously been investigated among siblings of children with cancer outside of qualitative studies. Consequently, some research presented may be from studies of siblings of children with other disabilities or illnesses, and research from the general population. This will be clearly explained.

**Personal circumstances**

This section captures those aspects of having a brother or sister with cancer that are relate to the situation they find themselves in following their sibling’s diagnosis. These have been divided into sub-categories: age, gender, disease variables, family size, pre-existing stressors, financial restrictions, and parental coping. All of these have been explored with siblings of children with cancer, some in more depth than others.

**Age**

Age has been examined a number of times in relation to sibling outcomes with results varying from study to study. In most studies, when significant relationships are found, siblings who are older at the time of measurement (but not adult) (Alderfer et al., 2009; Houtzager, Grootenhuis, et al., 2004; Houtzager et al., 2005), and who are elder in relation to their other siblings (Labay & Walco, 2004) tend to fare worse on measures of adjustment and emotional
distress than younger siblings. This trend has been exhibited in Dutch participants (aged 7-18) at both four to eight weeks post-diagnosis and 2-years post diagnosis (Houtzager, Grootenhuis, et al., 2004; Houtzager et al., 2005). This trend has been explained in two ways, firstly, elder siblings are more likely to take on more responsibility and make more personal sacrifices to assist their families (Labay & Walco, 2004; Sloper, 2000). Secondly, older siblings report being more emotionally involved with the illness (Houtzager, Oort, et al., 2004). However, in New Zealand, levels of depression and anxiety for siblings (aged 8-15) between two and seventeen months after diagnosis showed a negative correlation with age, suggesting older siblings had fewer emotional and adjustment problems than younger siblings (Dobson, 2007). The mean age in the New Zealand study was 10.46, (SD 1.97) with a small sample (N = 31) making it difficult to determine the representativeness of this finding. Given the international trends towards finding poorer psychological adjustment in adolescents compared to children (Alderfer et al., 2009) there is a need to more closely investigate this age group in New Zealand.

In terms of personal growth, older siblings appear to be more likely to experience post-traumatic growth. That is, they report more positive outcomes from cancer than younger siblings. This was evident on both self-report and parent-report. In a large-scale study of 254 siblings of children 6-42 months post-diagnosis, older siblings (aged 12-18) reported more positive outcomes from cancer than younger siblings (aged 5-11) (Sargent et al., 1995). In another aspect of the same study (the ‘Sibling adaptation to childhood cancer collaborative study’), parents were asked to report on behaviour change in their well-siblings (Barbarin et al., 1995). Parents of 10-18 year old siblings were significantly more likely to report that the sibling had increased in maturity and/or independence (over half of the parents reported this), compared to parents of four to nine year olds. Similarly, parents reporting on first-born siblings were more likely to report positive changes such as increased responsibility compared to parents reporting on middle or latest-born children (Barbarin et al., 1995). Increased age may contribute to a more complex understanding of cancer, contributing simultaneously to increased emotional distress and increased appreciation of perception of positive outcomes.

**Gender**

When gender has been examined in relation to adjustment of siblings of children with cancer, findings have either been non-significant (Dobson, 2007; Van Dongen-Melman et al.,
or indicated that sisters experience more problematic adjustment than brothers (Alderfer et al., 2009; Houtzager, Oort, et al., 2004). On occasion, even when there have been no main effects for gender, when gender and age are examined together, significant effects arise, usually showing older female siblings have the poorest outcomes, such as increased stress (Sahler et al., 1994) and higher depression and anxiety (Barrera, Fleming, & Khan, 2004). This is understood as relating to traditional gender roles and the increase in caregiving and housekeeping duties that older sisters often take on when their mother is occupied with tending to the patient (Sahler et al., 1994).

**Disease variables.**

A number of different aspects of the disease experience have been tested to see how they relate to variation in siblings’ psychological adjustment. Variables tested include time since diagnosis, type of diagnosis, and various different measures of illness intensity/severity. With the exception of time since diagnosis, these variables are usually unrelated to the measured outcomes of emotional and behaviour problems (e.g. Cohen, Friedrich, Jaworski, Copeland, & Pendergrass, 1994; Labay & Walco, 2004; Van Dongen-Melman et al., 1995).

The most important disease related predictor of outcomes across studies is time since diagnosis. Considering longitudinal studies only, a Dutch study of 83 siblings from 56 families (Houtzager, Oort, et al., 2004) found that although anxiety and parent-reported behavioural and emotional problems were not elevated one month after diagnosis, by 6-months post-diagnosis they were lower than a comparable reference group, and remained low at one year and two years post diagnosis. Quality of life was lower than the reference group at one month post-diagnosis, and improved, but remained low relative to the reference group until two years post-diagnosis at which time it reached a normal level. Self-report of behavioural-emotional problems (particularly the internalising subscale) showed slightly elevated risk one month post diagnosis but follow-up assessments were in the normal range (Houtzager, Oort, et al., 2004). A qualitative longitudinal study in the United Kingdom which interviewed 94 siblings approximately six and 18 months post-diagnosis found that by the second interview, most problems reported earlier had resolved, however for others, new problems had arisen (Sloper, 2000).

In a cross-sectional study, time since diagnosis was included in a regression predicting parent-reported internalising and externalising problems with other illness variables (the report
did not name the other predictors) (Cohen et al., 1994). Participants were 129 siblings of children diagnosed with cancer in the preceding four years. Time since diagnosis was the only significant predictor, accounting for 5.33% of variance in internalising scores, and 4.77% of variance in externalising scores (Cohen et al., 1994).

Although a number of studies have examined time since diagnosis, time since treatment end does not appear to have been tested previously, and many studies do not report on the treatment status of the patients/survivors (e.g. Houtzager, Oort, et al., 2004). When siblings are assessed 18 or 24 months from diagnosis, or even longer, a significantly lower percentage of the sample will have siblings completing active treatment than when assessed closer to the time of diagnosis. To reduce this potentially confounding factor, the current study will focus only on siblings of children who have completed treatment for cancer. Furthermore, analyses will include testing the influence of time since diagnosis and time since treatment ended.

In relation to this, bereaved siblings are often excluded from research regarding siblings of children with cancer due the impact of grief and difference in experience of these siblings. When included, they sometimes show quite different patterns of responding to siblings of patients and survivors. For example, Chesler et al. (1992) found bereaved siblings were much less likely to report positive impacts of cancer on themselves and their family. Consequently, this study focuses only on siblings of successfully treated cancer survivors.

**Family size**

The effect of family size has only been explored occasionally in this population. Labay and Walco (2004) found family size was significantly correlated with psychological adjustment (parent-reported behavioural and emotional problems) for 29 siblings from 20 families aged 7-16, on active treatment for acute myelocytic leukaemia, acute lymphoblastic leukaemia and non-Hodgkin’s lymphoma in the United States. This study never stated the range of family sizes in the study, or if measurement was continuous or categorical, and did not state the direction of the correlation. However the finding was discussed as larger family size increasing the complexity of relationships in addition to increased competition for resources (Labay & Walco, 2004) suggesting that siblings in larger families experienced poorer adjustment. Dobson’s New Zealand based study had a similar finding, that depression in siblings of children diagnosed with cancer in the previous 24 months was higher for siblings from larger families (five or more children)
compared to ‘smaller’ families (three to four children, only one family in the study had only two children). Of these two studies described, one study did not give enough information to interpret the finding and only tested a limited diagnostic population (Labay & Walco, 2004), and the second was unpublished (Dobson, 2007). Consequently, this is an important area for further investigation as these studies suggest it could be an important predictor of outcomes.

*Pre-existing/concurrent stressors.*

One well replicated finding in this field is that prevention of, and recovery from psychological problems for both parents and siblings is best when cancer is the only current stressor, and there were no pre-existing psychological or conflict issues in the family. Stressors include pre-existing illness, disability, or psychological problems in any family member, strained relationships, and difficult temperaments within the family which may be amplified by an experience such as cancer (Cuskelly, 1999; Zeltzer et al., 1996). Where families have additional stressors, these problems are often exacerbated by the cancer diagnosis, and family members become even more stressed. The extreme levels of resulting stress are related to poor psychological outcomes for siblings and parents (Dixon-Woods et al., 2005; Houtzager et al., 2005; Van Dongen-Melman et al., 1995). In terms of sibling adjustment, when parents were asked retrospectively about the sibling’s adjustment prior to the cancer diagnosis, pre-existing problems were the best predictor of current problems 6-42 months post-diagnosis (Sahler et al., 1994). Pre-existing health problems also significantly predicted quality of life one-month post diagnosis (Houtzager et al., 2005).

*Financial stressors.*

Cancer can put a large financial strain on the family (Dixon-Woods et al., 2005). New Zealand has a public health system, meaning patients do not pay for treatments or hospital stays personally, and parents can stay at Ronald McDonald house free of charge while their child is in hospital (Ronald McDonald House Charities NZ). However, there are many additional expenses such as travel costs, supplementary therapies, food for special diets, and child-care for well-siblings which are not covered by the public health system (Dockerty, Skegg, & Williams, 2003).

Dockerty et al. (2003) studied the financial impact of child-cancer in New Zealand for 237 families with a child diagnosed between 1990 and 1993. Parents were asked to report on cancer-related expenses in the month preceding questionnaire completion. All participants were within
three years of diagnosis, 86% had children who were well or in remission, but 19% had children who had died from cancer. Nearly three quarters (73%) of the families with living children reported some cancer related expenses, of this group, the average amount spent in the previous month was NZ$302 (SD NZ$353). A median spend was not given. Some financial compensation could be claimed for these expenses but the mean shortfall after receiving compensation was NZ$157. Most of this money was on undefined expenses but significant proportions were on “home help”, “accommodation for family or child” and “transport, travel and parking”. The amount spent was unrelated to distance between home and treatment centre, but was significantly associated with number of days in hospital. Note, however, at the time of data collection there were five treatment centres spread out across the country (Dockerty et al., 2003), and now there are only two, meaning more families will be travelling further distances now than they were in 1990-1993. According to Dockerty et al. (2003), for those with information available (n = 171), cancer-related expenses represented on average 13% of the after-tax-family-income. Furthermore, 37% of families had had to borrow money as a result of financial effects of cancer (Dockerty et al., 2003). These statistics overall show child cancer can be a financial burden on families in New Zealand.

Decreased financial freedom affects sibling psychological adjustment through access to resources which may support positive sibling adjustment. For siblings, having alternative care arrangements (Seligman & Darling, 2007), being able to go on family outings, and continuing with social programs (sports teams, music lessons, scouts etc.) (Sidhu et al., 2005), may mitigate the negative impact of cancer in their lives. Financial limitations also limit siblings’ access to visit their brother or sister. In research on parents of children with cancer in New Zealand lowered emotional health was associated with unemployment and limited social support (Dockerty, Williams, McGee, & Skegg, 2000). In another study, in the United States, family income was a significant predictor of variance of parent-reported sibling internalizing (9.56%) externalising (8.82%) and social competence (5.22%) with lower incomes predictive of more problems (Cohen et al., 1994).

*Parental coping.*

Amplified by financial strain, parents’ stress and emotional reactions to their child’s diagnosis and treatment may also impact on siblings. Parental anxiety, depression, and marital
conflict are commonly reported in the first 12 months after diagnosis (Dixon-Woods et al., 2005). In previous studies these variables have been highly related to sibling psychological adjustment. One study stratified 170 siblings into four bands depending on their level of parent-reported behavioural/emotional disturbance 6-42 months after their sibling’s diagnosis (Sahler et al., 1997). Mothers of siblings stratified into the ‘dysfunctional’ group had the lowest levels of wellbeing (Sahler et al., 1997). Furthermore, in a study using regressions to predict psychological adjustment of siblings, maternal depression accounted for 14.1% of internalising and 17.43% of externalising problems as reported by parents (Cohen et al., 1994). However, in interpreting these findings, the source of data must be considered, as in another study of 83 siblings (aged 7-19) 1-24 months post-diagnosis, parental distress was associated with parent-reported behavioural/emotional problems, but not sibling-reported behaviour/emotional problems (Houtzager, Oort, et al., 2004). The relationship between parent-reported psychological adjustment and parental mental health/distress may occur because distressed or mentally unwell parents may be more likely to perceive their well-child’s behaviour as problematic, or more likely to assume that because they are experiencing emotional distress that the sibling is also experiencing emotional distress. For this reason the present study will use sibling reports of all measures to reduce the potential for parental distress to influence results.

A New Zealand based study compared mental health of parents of children with cancer (218 mothers, 179 fathers) with parents of 303 controls (Dockerty et al., 2000). Parents of children with cancer reported statistically significantly poorer mood ratings, and mothers of children with cancer rated their social life significantly lower than mothers of controls. Although these differences were statistically significant, the magnitude of these differences were not clinically significant (Dockerty et al., 2000). This study suggests parental pathology may not be an important factor of sibling adjustment in New Zealand as parental pathology may be relatively rare. However, this study did not report rates of parents in clinical or at-risk ranges. Among sibling measures, means between sibling groups and comparison groups are not always significant, but rates of siblings with scores indicating significant maladjustment are often elevated (Alderfer et al., 2009). Mental health of parents of children with cancer in New Zealand still requires more research, but the Dockerty et al. (2000) study suggests it not likely to be a problem which effects many siblings of children with cancer in New Zealand.
**Individual coping style**

When facing adversity such as a sibling being diagnosed with and treated for cancer, siblings must find a way to cope with these events. Many different strategies are employed by siblings to deal with their experiences. A few studies have examined different coping styles used by siblings, and how these different strategies relate to their overall psychological adjustment. Coping styles that have been examined include optimism, contributing to supporting the family, acquiring knowledge about the patient’s illness and treatment, and keeping their problems to themselves (Chesler et al., 1992; Dobson, 2007; Houtzager et al., 2005; Houtzager, Oort, et al., 2004; Nolbris et al., 2007). A summary of this research on coping styles is given below.

**Positive expectations**

Expecting the best is a common coping strategy among siblings (Houtzager et al., 2005) (Nolbris et al., 2007). Optimism and hope appear to be positive coping strategies, associated with a number of elements of positive adaptation. The New Zealand study of 37 siblings aged 8-15 within 17 months of diagnosis found results from a measure of dispositional hope were positively correlated with benefit finding, emotional control, and disclosure (Dobson, 2007). These results suggest that siblings who expect the best from their lives are better able to control their emotions, more likely to discuss their problems with other people, and more able to find positive outcomes from their experience with cancer. However, hope was not significantly correlated with depression or anxiety. Although hopeful siblings are more likely to perceive positive outcomes, they are just as likely to experience poor psychological adjustment. Levels of hope also increased with time since diagnosis and the sample overall had lower hope than found in previous studies including ill and healthy populations (Dobson, 2007). Considering this, the role of hope may change depending on the treatment status of the patient, and as yet it has not been examined in a specific sample of siblings of cancer survivors. Finally, the hope measure used (Children’s Hope Scale) did not ask about expectations of the future, and also had a very personal focus, in that it was about the success and agency of the child. These aspects of hope may be less relevant to coping in this population where their hopes are for positive outcomes for themselves and their family, and their agency in effecting positive outcomes such as their sibling’s survival and comfort is very limited. Consequently, the present study will use a measure of optimism, rather than hope, to measure the effect of positive expectations of the future.
Another study assessed illness focused coping strategies, including ‘predictive control’ which referred to having positive expectations about the illness (Houtzager et al., 2005; Houtzager, Oort, et al., 2004). One month following diagnosis, predictive control was the only coping style associated with positive outcomes; those who expected their sibling would improve experienced more positive emotions and fewer negative emotions than siblings with lower levels of predictive control (Houtzager et al., 2005). A follow-up report, which reported on findings across four data collection points (one month, six months, 12 months and 24 months after diagnosis) reported predictive control was associated with lower anxiety, lower insecurity, lower loneliness and less emotional involvement in their sibling’s treatment (Houtzager, Oort, et al., 2004). This report did not make it clear at what time point(s) predictive control or the associated outcomes were measured, so it is unknown how the coping strategies used varied across time-points and treatment status, and whether the coping style was more or less important in predicting adjustment at any particular time (Houtzager, Oort, et al., 2004). Further research is needed to clarify the role of positive expectations in predicting psychological adjustment after treatment has ended.

**Contributing to the family.**

Siblings sometimes struggle to find a way to contribute to their siblings cancer treatment plan in a meaningful way (Dixon-Woods et al., 2005). Consequently, some siblings cope by working to help their family by taking on extra responsibilities (Chesler et al., 1992). This ‘parentification’ can range from doing slightly more chores to make up for the patient being unable to do them, (Spinetta et al., 1999), to taking almost complete responsibility for household management and care of younger siblings (Faulkner et al., 1995; Nolbris et al., 2007; Woodgate, 2006). Typically, elder siblings and females are most likely to be parentified, and this is used to explain some of the gender and age/birth order variations in adjustment described earlier. Parentification is a difficult concept to measure and to my knowledge has not been assessed quantitatively. In previous qualitative research, parents have expressed guilt at the level of extra responsibility well-siblings have taken on (J. M. Patterson et al., 2004), but when siblings have been interviewed they have said that helping made them feel good (Chesler et al., 1992; Woodgate, 2006), and that they wished they could have helped more (Woodgate, 2006). Younger siblings sometimes express distress with how helpless they feel because their ability to
support the family is limited (Chesler et al., 1992). When females and older siblings are seen to have poorer outcomes, this is often seen as a consequence of parentification, but this is in direct contrast with sibling’s appraisals of the effect of being able to help and having a role in the family. This difference of interpretation between quantitative and qualitative research supports the use of mixed-methods which allows siblings’ voices to be incorporated into the story told by statistics.

Knowledge/information about the patient’s illness.

Some siblings cope with their experiences by endeavouring to find out as much as possible about what is happening to the patient. The International Society of Paediatric Oncology (SIOP) Working Committee on Psychosocial Issues in Paediatric Oncology has created guidelines for assisting siblings of children with cancer (Spinetta et al., 1999). These guidelines have a strong emphasis on information and communication, emphasising the importance of giving siblings full and accurate information appropriate to their developmental level and demonstrated interest, with a focus on how cancer may impact on them and their interactions with the patient (see Spinetta et al., 1999). Furthermore, an explicit goal of some sibling interventions including camps and support groups is to increase knowledge of cancer with the assumption that an increase in knowledge is a positive outcome (Prchal & Landolt, 2009; Sidhu et al., 2006). Reasons given for giving information are that it can make siblings feel included (Spinetta et al., 1999) and may decrease stress and anxiety from a fear of the unknown (Prchal & Landolt, 2009; Sidhu et al., 2006). The risks of keeping information from siblings are that siblings may make assumptions or seek information that may be more harmful than the truth their parents may tell them (Faulkner et al., 1995; Seligman & Darling, 2007; Spinetta et al., 1999).

The need for more information is mentioned by siblings in a number of qualitative studies (Sloper, 2000; Wilkins & Woodgate, 2005) but findings from quantitative studies are mixed in terms of how helpful more information is. Positively, one study with 60 siblings of survivors found that siblings (aged 5-16) who reported greater levels of communication around the cancer also reported that cancer had less of an impact on their life (Van Dongen-Melman et al., 1995). Another study had more neutral findings: knowledge and understanding of cancer for 7-16 year old siblings of children on active treatment was not significantly associated with parent-reported psychological adjustment, but it was positively correlated with empathy. Empathy was then a
significant predictor of adjustment (total problems measured by the CBCL and externalising problems) (Labay & Walco, 2004). However, in the longitudinal Dutch study (mentioned above in relation to positive expectations) (Houtzager et al., 2005), siblings who relied more on ‘interpretative control’; a coping style of trying to understand cancer and find explanations for the illness, experienced significantly fewer positive emotions one month after diagnosis (Houtzager et al., 2005). In the follow-up report, including data from two years of measurement, interpretative control was positively associated with insecurity and emotional involvement (Houtzager, Oort, et al., 2004). Again the time of data-collection for these different constructs was not given. Interpreting these apparently conflicting studies, it is possible that it is not information by itself that predicts better adjustment in siblings, but the process of communication with parents, and feeling like they are being heard and are able to ask questions that supports positive sibling adjustment.

*Keeping their problems to themselves/minimisation.*

In qualitative studies, sibling of children with cancer have often described an acute awareness of their parents’ stress levels, and behaving in such a way so as not to stress their parents further (Chesler et al., 1992). Combined with a lack of time with their parents and due to the illness demands, this often meant that siblings do not talk about their feelings and emotions in relation to the cancer (Heffernan & Zanelli, 1997; Woodgate, 2006). Additionally, many siblings report needing someone outside of the family who they could talk to about their own worries (Dixon-Woods et al., 2005; Faulkner et al., 1995). But often, those outside the family are concerned about the patient, and talk to the siblings only about how their brother or sister is progressing, rather than how the progression is impacting on the sibling (Spinetta et al., 1999).

Dobson’s (2007) New Zealand based study of 31 siblings of children diagnosed in the past 18 months measured sibling disclosure: how much they have discussed thoughts and feelings about their sibling’s cancer with various people; and non-disclosure: how much they have hidden thoughts and feelings about their sibling’s cancer from people. Findings indicated that levels of both disclosure (sharing) and non-disclosure (hiding) were low, suggesting siblings may be willing to talk, but have few opportunities to talk about their thoughts and feelings about their sibling’s cancer. Disclosure/non-disclosure levels were not correlated with any outcomes relating to psychological adjustment (Dobson, 2007). It appears that many siblings do not talk to their
parents about their thoughts and feelings related to cancer, therefore, it is important that research on their wellbeing uses sibling self-report, as parents may be unaware of problems with psychological adjustment in their well-children.

**Parental differential treatment.**

Differential treatment is the degree to which one sibling is treated differently from the other. Siblings typically find that during and after their sibling’s treatment, that the patient receives much more attention, affection, and less discipline than them, from both parents and community members (Chesler et al., 1992; Sidhu et al., 2005; Sloper, 2000; Spinetta et al., 1999; Wilkins & Woodgate, 2005). As parents and health care professionals give their attention to the child who is unwell, the sibling may feel left out, unworthy, neglected and/or resentful (Chesler et al., 1992; J. M. Patterson et al., 2004; Sidhu et al., 2005; Spinetta et al., 1999; Woodgate, 2006). In qualitative research with parents, parents have discussed the difficulty balancing many conflicting demands during their child’s treatment, and the struggle to meet everyone’s needs including those of well siblings (J. M. Patterson et al., 2004; Sidhu et al., 2005).

In qualitative studies with siblings as participants, parental differential treatment is reported in relation to both attention/affection and control/discipline (Chesler et al., 1992; Sloper, 2000) and often explored in relation to feelings of jealousy and resentment. One study interviewed 6-21 year old siblings ($N = 30$) at various different stages of treatment; some siblings were interviewed twice, and one focus group was held (Woodgate, 2006). Although siblings become jealous while the patient is on treatment, none exhibited any long-lasting resentment (Woodgate, 2006). Another study interviewed 94 siblings approximately six-months after diagnosis and 64 of the same siblings approximately one year later (Sloper, 2000). They found that loss of attention and status was reported much more at time one than time two, and that up to one third of the siblings said they did not mind the change. Siblings who understood differential treatment occurred because the illness were more accepting of the differences in treatment (Sloper, 2000). A third study also reported on parental differential treatment, finding that many participants reported parental differential treatment, and were jealous of their sibling because of it (Chesler et al., 1992). This study, which interviewed 21 siblings aged 10-21, did not report time since diagnosis or treatment status although six participants were bereaved siblings. In this study, jealousy was reported as remaining even when siblings understood why the parental
differential treatment occurred. Furthermore, this study highlighted that many siblings felt guilty for feeling jealous or resentful (Chesler et al., 1992). Overall, it seems that siblings struggle with conflicting thoughts and feelings about parental differential treatment, and that although they may understand the reasons for it occurring, it can also be challenging to deal with.

Although parental differential treatment is regularly identified as central to siblings’ experiences of cancer, it has not been previously been examined quantitatively in families of children with cancer. The closest is a study which examined the physical health of siblings, finding that 6-42 months post-diagnosis, compared with a control group, parents of children with cancer were less likely to take a sibling to the doctor when they complained of various types of ill-health (Zeltzer et al., 1996). Presumably they would not show the same hesitancy with taking the child with cancer to a doctor. In the New Zealand study of siblings of children with cancer, parental differential treatment was identified by participants as an important area for follow-up study (Dobson, 2007).

*Family cohesion.*

Increased family cohesion and closeness is commonly listed by both parents and siblings as a positive outcome of child cancer in qualitative research (Aldberfer et al., 2009; Chesler et al., 1992; Prchal & Landolt, 2009; Sargent et al., 1995; Sloper, 2000; Woodgate, 2006). Many of the same studies also report difficulties in relationships within the family such as feelings of loneliness within the family (Chesler et al., 1992), deterioration in the sibling relationship (Sloper, 2000), conflict with parents (Sloper, 2000), and hiding feelings from parents to protect them from further stress (Woodgate, 2006).

Increased family cohesion is generally grouped with personal growth as a positive outcome from cancer (e.g. Wilkins & Woodgate, 2005), however the evidence on the impact of family cohesion on sibling psychological adjustment is not clear cut. A qualitative study noted that keeping the family together was a primary goal for many siblings, explaining many of their behaviours including parentification, acceptance of parental differential treatment, and non-disclosure (Woodgate, 2006).

In general, family cohesion and adaptability are expected to hold a U-shaped relationship with adaptation, with extremely high and extremely low scores equally associated with poor outcomes for children (Cohen et al., 1994). However, among families with a child with cancer, at
least three studies have found linear relationships between adjustment and family cohesion and adaptability with more cohesion and adaptability associated with better sibling adjustment. The first two studies used the same measure, (FACES-II) although in slightly different ways. In the first study, 129 families of siblings aged 4-16 with living siblings diagnosed within the past four years were analysed (Cohen et al., 1994). Families were categorised into groups of ‘disengaged’, ‘connected’ and ‘enmeshed’ for cohesion, and into groups of ‘rigid’, ‘flexible’ and ‘chaotic’ regarding adaptability. Siblings from enmeshed families had the fewest externalising problems and highest social competence, followed by flexible, then disengaged families. Siblings from chaotic families had significantly fewer externalising problems and better social competence, than either flexible or rigid families, who did not differ on these domains (Cohen et al., 1994). In the second study, which examined siblings of pre-school age with a sibling diagnosed ‘recently’ but at least 6-months prior to the interview, due to a smaller sample size ($N = 25$), adaptability and cohesion were scored as continuous variables (Horowitz & Kazak, 1990). Adaptability was negatively correlated with total behaviour problems and externalising, and cohesion was negatively correlated with total behaviour problems, internalising, and externalising (Horowitz & Kazak, 1990). Finally, the third study assessed siblings of children diagnosed with cancer 6-42 months previously (35 from Israel and 35 from the United States) (Dolgin et al., 1997). Correlational investigations showed family support and family expressiveness were both significantly negatively correlated with internalising, externalising, and total-problem scores, Family conflict was positively correlated with internalising, externalising and total-problem scores. In regressions, family supportiveness accounted for 33% of variance in externalising problems, 42% of variance in internalising problems, and 54% of the total-problems score (Dolgin et al., 1997). All three of these studies were cross-sectional.

In direct contrast, the Dutch longitudinal study used the Dutch version of the FACES instrument, scoring adaptability and cohesion as continuous variables with 83 siblings aged 7-19 years assessed at four time-points from 1-month to two-years (Houtzager, Oort, et al., 2004). In this study anxiety and insecurity were positively related to both family adaptation and cohesion, self-reported problem behaviours were positively correlated with cohesion, and sibling quality of life was negatively correlated with cohesion. The time-points at which the various variables were measured was not given (Houtzager, Oort, et al., 2004). The authors of the Dutch study addressed their conflicting findings to those of Cohen et al. (1994) and Horowitz and Kazak
(1990): they suggested that while high adaptability and high cohesion may be helpful at an immediate time-point, a chronic state of flux as in families high in adaptation, may indicate instability and be experienced as unsupportive by siblings (Houtzager, Oort, et al., 2004). They did not address differences found in terms of cohesion.

In conclusion, the findings of the impact of family cohesion and adaptability are conflicting. More research is required to learn more about the relationships held between family relationships and sibling psychological adaptation. Furthermore, all of these studies have examined only the family as a whole, without looking at specific relationships within the family. Examining dynamics of different relationships, such as the sibling relationship, and the parental relationship, may increase understanding of the aspects of the family which are important in influencing sibling adaptation.

**Sibling relationship.**

Very few studies within the research field of siblings of children with cancer have actually considered the sibling relationship when considering psychological adjustment of siblings. This is surprising given that it is this relationship that has led to their being the subject of research. In the previous study in New Zealand, aspects of the sibling relationship were suggested by participants as an important area for follow-up study (Dobson, 2007).

Some qualitative studies have emphasised the change in the dynamics of the sibling relationship, such as decreases in intimacy and companionship (Sloper, 2000), and loss of status relative to the patient (Chesler et al., 1992). Other studies have emphasised the increase in importance siblings attribute to the sibling relationship following their brother or sister’s diagnosis (Nolbris et al., 2007; Woodgate, 2006). The studies noting (mostly negative) changes in the relationship both took place a number of years before the studies documenting the increase in importance of the sibling relationship. The differences between these studies may represent the impact of changes in how child-cancer is treated in hospitals. Increasingly, the family is seen as the unit of treatment for child-cancer, considering psychosocial aspects of treatment, as opposed to a focus on the illness in isolation (Meyler, Guerin, Kiernan, & Breatnach, 2010; Monterosso, 2001). This means siblings are more informed and more involved in treatment, and medical teams are more likely to consider the impact of cancer on siblings. None of these studies have established how sibling relationships might relate to the overall adjustment of siblings but
most research has assumed that increases in warmth and pro-social behaviours between siblings are positive findings (Nolbris et al., 2007; Woodgate, 2006).

Conversely, when examined quantitatively, higher sibling warmth was associated with poorer outcomes. A study of 29 siblings (aged 7-16) from 20 families with a child on active treatment for acute myelocytic leukaemia, acute lymphoblastic leukaemia or non-Hodgkin’s lymphoma asked siblings and patients to report on their sibling relationship, and asked parents to report on sibling psychological adjustment (internalising, externalising and social competence) (Labay & Walco, 2004). Warmth of the sibling relationship, as reported by both siblings and patients, was negatively correlated with sibling social competence, and patient-reported warmth was negatively correlated with sibling total problem scores and sibling externalising (Labay & Walco, 2004). These results suggest a close, warm, sibling relationship may hinder adjustment in siblings. Given the lack of research on sibling relationships, and the surprising finding from Labay and Walco (2004), this is an area of sibling experience that requires further investigation.

**Peer/community relationships.**

Siblings, particularly adolescent siblings, hold important relationships outside the family which may also be influential in terms of their adjustment. These include relationships with age peers, and interactions with the wider community. When the rest of the family is occupied with the patient, these relationships outside the family can be particularly important for supporting positive psychological adjustment in siblings (Sloper, 2000).

When social support of siblings has been examined, higher social support has been associated with decreased anxiety, fewer behaviour problems, and fewer symptoms of depression among 6-18 year olds whose siblings were undergoing treatment ($N = 72$) (Barrera et al., 2004). In a different study, 161 siblings (aged 8-18) of children 3-38 months post-diagnosis rated the support they received from various sources and the relative importance of these sources of support (Alderfer & Hodges, 2010). Support from friends was rated by siblings as more plentiful and more important than support from any other source (parents, teachers, classmates and ‘others in school’). Nevertheless, friend support was unrelated psychological adjustment (sibling reported anxiety, depression, and post-traumatic stress, and parent reported internalising and externalising). However, classmate support and support from ‘others in school’ were significantly negatively correlated with depression and anxiety (Alderfer & Hodges, 2010).
These findings are inconclusive in terms of the role peers may play in the adjustment of siblings of children with cancer, highlighting this as an area that requires further investigation. Understanding the role peers play in adjustment may be particularly important in light of qualitative findings that peer relationships can break-down following a sibling’s diagnosis. A number of reasons contribute to the disruption in peer relationships. Firstly: limitations on access: lack of time, transport, and stricter financial restraints can restrict siblings’ ability to enjoy their friends company (Alderfer et al., 2009; Barbarin et al., 1995; Faulkner et al., 1995). Secondly, siblings can feel torn between spending time with their family and the patient, and spending time among friends (Nolbris et al., 2007). Thirdly, peers may tease the sick child, especially around changes in appearance (Barbarin et al., 1995). Parents often report that the patient’s peers are insensitive to the illness, rather than helpful or supportive (J. M. Patterson et al., 2004), similar patterns may occur with siblings’ peers.

**Professional intervention.**

Despite the lack of conclusive findings about what supports positive psychological adjustment and what protects from negative psychological adjustment in siblings of children with cancer, there are a number of interventions which aim to support the positive psychological adjustment of siblings (Prchal & Landolt, 2009). These interventions include camps (Murray, 2001; Packman et al., 2004; Sidhu et al., 2006), support groups (Nolbris, Abrahamsson, Hellstrom, Olofsson, & Enskar, 2010), and internet-based support (Prchal & Landolt, 2009), many of which have not been evaluated (Prchal & Landolt, 2009). In New Zealand, different charities run camps, family days, and other activities for siblings and other family members.

Interventions for siblings have varied in their goals. Some aim to increase medical knowledge (Sidhu et al., 2006), others have focused on supporting siblings to cope positively with their experiences (Nolbris et al., 2010), still more have emphasised the importance of building relationships with similar others (Prchal & Landolt, 2009; Sidhu et al., 2005). Those that have been evaluated have used measures of various aspects of psychological adjustment to determine success, including self-esteem, anxiety, depression, quality of life, and social adjustment (Prchal & Landolt, 2009). Prchal and Landolt (2009) recently conducted a systematic review of interventions for siblings. They concluded that parent and sibling satisfaction with interventions was generally high, and involvement in interventions was associated with
decreased depression, and improved medical knowledge and health-related quality life for siblings. Findings regarding self-esteem, anxiety, behavioural problems and social adjustment depended on the intervention (Prchal & Landolt, 2009).

**The present study**

The present study aims to describe and examine the psychological adjustment of adolescent siblings of cancer survivors in New Zealand and contribute to the growing knowledge of experiences for siblings of children with cancer. This study addresses several limitations evident in the existing literature.

Firstly, this study assesses experiences of siblings of cancer survivors, rather than cancer patients. Most research focuses a period relatively close to diagnosis, usually within three to four years. This approach ignores the long-term impact of having a sibling who has had cancer. Furthermore, treatment status is often not reported, and siblings of children on treatment, in remission and children who have died are grouped together for analysis. This ignores the very different current life situations of these siblings, and the influence this could have on their psychological adjustment.

Secondly, this research will take place in New Zealand. Siblings of children with cancer have only been studied once before in New Zealand (Dobson, 2007). Every country has a different culture and expectation of the sibling relationship and countries differ in treatment provision, accessibility of services, and support for families and siblings. The applicability of international research to New Zealand siblings has not been established. Initial research suggests New Zealand siblings may experience more problems with negative adjustment than siblings from other countries (Dobson, 2007).

Thirdly, this study examines the siblings’ perspectives of their own wellbeing. Although many studies have done this before, many have only used parental report. Furthermore, it is important that siblings have a chance to have their voice heard, this is particularly relevant in this population where siblings’ voices are marginalised both within in and outside of their family. Siblings have been shown to lose their ‘sense of self’ in relation to their sibling and parents (Woodgate, 2006), so research which addresses them directly is important.

The fourth strength of this study comes from the psychological adjustment variables it assesses. Rather than being limited to measures of negative adjustment, this study assesses
depression, self-esteem and wellbeing. These three variables represent an aspect of negative adjustment, an aspect of positive adjustment, and an overall measure of global adjustment. Specifically, the depression scale measures symptoms of psychopathology, the psychological wellbeing scale is a holistic measure which allows measurement of siblings who are thriving, not just siblings who are poorly adjusted. The self-esteem scale also reduces the emphasis on poor adjustment and outcomes. Self-esteem may be particularly relevant for this population who have been known to identify themselves in relation to their brother or sister rather than developing a positive sense of self as separate from their family (Woodgate, 2006).

Finally, this study analyses the impact of important relationships in the siblings’ lives on psychological adjustment. Some relationships, such as the sibling relationship and peer relationships have only been examined quantitatively on very few occasions among siblings of children with cancer. Parental differential treatment has not been examined at all among siblings of children with cancer.

Specific aims of this research are:

1. To gain awareness of the psychological adjustment status of adolescent siblings of children and young people who have cancer in remission in New Zealand.
2. To explore a range of demographic, individual, and relational factors that may be associated with the psychological adjustment of adolescents who have a sibling who had cancer.
3. To explore siblings’ perspectives of what made their experience more difficult, and what was helpful to them in supporting positive adjustment.
4. To use the data gathered to identify ways to support positive adaptation among adolescent siblings of cancer survivors.

To meet these aims, a research method was chosen which incorporated both a quantitative questionnaire study and qualitative interview study.

The questionnaire study will incorporate a number of psychometric measures assessing depression, self-esteem and wellbeing as outcomes. This questionnaire will also assess optimism, parental differential treatment, sibling relationships, and peer relationships. As described above, all these variables have been identified by previous research as potentially influential in explaining or understanding variations in sibling adjustment. The resulting data will be used to identify factors that put siblings at risk of poor psychological adjustment, and which support positive adjustment.
The interview study will be completed following the questionnaire study and will ask siblings to describe their experiences as a sibling of someone with cancer, with a particular focus on aspects of their experience which they found helpful and unhelpful for dealing adaptively with cancer in the family. The interview study is included to identify if New Zealand siblings report similar strengths and difficulties as siblings internationally, and to capture some of the variability in experiences between siblings. Furthermore, the richness of qualitative data contributes to a deeper understanding of dynamics that may be observed but not understood through quantitative data.

In common with previous studies with siblings of children with cancer and other disabilities and illnesses, this study was atheoretical. There are some theories which address the experience of illness and examine similar constructs to those used in this study, for example the “Woman to Woman Conceptual model for adaptation to chronic illness” (Weinert, 2008). However, this model and others like it are typically developed for specific populations (e.g. chronically ill, rural, middle-aged women). Furthermore, they are focused on adaptation of the unwell family member, and tend to address adult populations. As no theories matched the current study’s population the rationale for inclusion of constructs in this study was based on previous research, particularly qualitative research with siblings. The results of this study, which includes more constructs than many previous studies, may prove to be important in developing a theoretical model that applies to siblings. This will be an important step in developing this field of study.
Chapter Two: Method for the Questionnaire Study

Chapter overview.

This chapter will describe the participants, questionnaire design, and procedures used to recruit participants for the quantitative study. It also includes the statistical analysis plan.

Participants

Questionnaires were collected from 31 adolescent siblings of cancer survivors in New Zealand. The sample consisted of 20 females and 11 males, aged between 12 and 18 years ($M = 14$ years $10$ months). Participants were able to identify more than one ethnicity; most of the sample selected Pākehā/New Zealand European as one of their ethnicities ($N = 26$), four participants named other European ethnicities, and four included Maori as an ethnicity. One participant listed their ethnicity as “Asian (Korean)”. Participants were between four years younger, and nine years older than their sibling who had cancer, ($M = two$ years six months older, $Mdn = three$ years older). To ensure independence of cases only one child per family was permitted to participate.

To determine eligibility for the study, participants were required to confirm the following: that they had a brother or sister who had been diagnosed with cancer; that this brother or sister was currently discharged off treatment, in remission; and that they currently lived with this sibling.

The average health of participants, rated by parents on a 1-10 scale where 1 = poor health and 10 = excellent health was 8.96 ($SD = 1.22$). This was slightly higher than parents’ ratings of the child who had cancer whose average health rating was 8.11 ($SD = 2.00$).

Information regarding the cancer showed that of those with information available ($n = 27$)$^1$, 10 of the participants’ siblings had only one type of treatment, a further eight had two modes of treatment, six had three modes of treatment, and three had four modes of treatment. One participant was a bone-marrow donor, and two others had blood tests in relation to their sibling’s

$^1$ Parents of three participants (aged over 16) did not return parent questionnaires. One parent returned the parent questionnaire but had selectively missed all questions relating to the child with cancer.
cancer, no other participants underwent any medical procedures in relation to their sibling’s cancer. On average, the patient/survivor was diagnosed with cancer 5 years 5 months ago (range 5 months - 17 years 8 months) and finished treatment 4 years, 3 months ago (Range = 3 months - 15 years 6 months). Three survivors have had more than one bout of cancer.

**Materials**

Two questionnaires were created for this study, the parent questionnaire, and the sibling questionnaire. Both questionnaires were available in hardcopy form, or online through Survey Monkey. Survey Monkey is a computer program which provides an interface for surveys to be conducted online. It is confidential, accessed by a password, and allows researchers to edit the pages and survey design according to their needs. Competent English and a 12 year old reading level were required for both questionnaires.

The parent questionnaire (see Appendix A) asked three demographic questions, (age, gender, and ethnicity) about the child who has had cancer, and six questions regarding the cancer that child had (type of cancer, dates of diagnosis and treatment end, treatment types, and current health status). Parents were also asked to rate the sibling’s current health status on a scale of 1-10, and any medical involvement they had in relation to their brother or sisters cancer (e.g. being tested for donor compatibility). Finally, three questions from the Woman Abuse Screening Tool (Brown, Lent, Brett, Sas, & Pederson, 1996) were asked. These questions asked about the atmosphere in the home, the difficulty associated with working out arguments, and the structure and routine of people in the home. The data resulting from these questions was incomplete so they were not used in analyses. The parent questionnaire was expected to take less than five minutes to complete.

The sibling questionnaire (see Appendix B) began by re-checking eligibility, followed by questions about age, gender, ethnicity, and their siblings’ ages and genders. These questions were followed by a number of psychological measures which are discussed below. The sibling questionnaire was estimated to take between 20 and 30 minutes to complete. See Table 1 below for a summary of the measures used in the sibling questionnaire including sample items. Depression, Self-esteem and wellbeing were identified as assessing psychological adjustment.
Table 1

Measures included in sibling questionnaire including their source, sample items, scale and scoring method

<table>
<thead>
<tr>
<th>Measure (source)</th>
<th>No. Items</th>
<th>Sample item</th>
<th>Calculation of final score</th>
<th>Scale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Centre for epidemiological studies depression scale-children (CES-DC) (Weissman, Orvaschel, &amp; Padian, 1980)</td>
<td>20</td>
<td>I felt down and unhappy.</td>
<td>Mean of all items</td>
<td>0-3 “not at all” to “A lot”</td>
</tr>
<tr>
<td>Rosenberg self-esteem scale (RSE) (Rosenberg, 1965)</td>
<td>10</td>
<td>At times I think I am no good at all.</td>
<td>Mean of all items</td>
<td>4 points, “Strongly agree” to “Strongly disagree”</td>
</tr>
<tr>
<td>Psychological Wellbeing scale (Ryff &amp; Keyes, 1995)</td>
<td>18</td>
<td></td>
<td></td>
<td>1-6 “strongly disagree” to “strongly agree”</td>
</tr>
<tr>
<td>Autonomy</td>
<td>3</td>
<td>I have confidence in my opinions, even if they are contrary to the general consensus.</td>
<td>Mean of all items after reverse scoring negatively worded items</td>
<td></td>
</tr>
<tr>
<td>Environmental Mastery</td>
<td>3</td>
<td>I am quite good at managing the many responsibilities of my daily life.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Personal Growth</td>
<td>3</td>
<td>I think it is important to have new experiences that challenge how you think about yourself and the world.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Positive Relations With Others</td>
<td>3</td>
<td>People would describe me as a giving person, willing to share my time with others.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Purpose In Life</td>
<td>3</td>
<td>Some people wander aimlessly through life, but I am not one of them</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-Acceptance</td>
<td>3</td>
<td>I like most aspects of my personality</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Life optimism test/ Life orientation test (LOT) (Scheier &amp; Carver, 1985)</td>
<td>8</td>
<td>In uncertain times, I usually expect the best.</td>
<td>Mean of 8 items after reverse scoring negatively worded items</td>
<td>0-4 strongly disagree to strongly agree</td>
</tr>
</tbody>
</table>


<table>
<thead>
<tr>
<th>Measure (source)</th>
<th>No. Items</th>
<th>Sample item</th>
<th>Calculation of final score</th>
<th>Scale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sibling inventory of differential experience; Perceived parental differential treatment (SIDE) (Daniels &amp; Plomin, 1985a).</td>
<td>18</td>
<td></td>
<td></td>
<td>5 point scale, “My sibling much more than me” to “me much more than my sibling”</td>
</tr>
<tr>
<td>Relative maternal affection</td>
<td>5</td>
<td>Whose thoughts and feeling has your mother been most sensitive to?</td>
<td>Mean response calculated for each scale</td>
<td></td>
</tr>
<tr>
<td>Relative maternal control</td>
<td>4</td>
<td>Who has your mother been most strict with?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relative paternal affection</td>
<td>5</td>
<td>Whose thoughts and feeling has your father been most sensitive to?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relative paternal control</td>
<td>4</td>
<td>Who has your father been most strict with?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relative parental affection</td>
<td>10</td>
<td>As above</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relative parental control</td>
<td>8</td>
<td>As above</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Perceived fairness of differential treatment (Kowal, Kramer, Krull, &amp; Crick, 2002).</td>
<td></td>
<td>Do you think [this parent’s] behaviour here is fair?</td>
<td>Unfair = 1 Fair = 1</td>
<td>Dichotomous, Fair/Unfair</td>
</tr>
<tr>
<td>Parental total unfairness</td>
<td>18</td>
<td>Mean of responses</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Maternal affection unfairness</td>
<td>5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Maternal control unfairness</td>
<td>4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Maternal total unfairness</td>
<td>9</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Paternal affection unfairness</td>
<td>5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Paternal control unfairness</td>
<td>4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Paternal total unfairness</td>
<td>9</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parental affection unfairness</td>
<td>10</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parental control unfairness</td>
<td>8</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Measure (source)</td>
<td>No. Items</td>
<td>Sample item</td>
<td>Calculation of final score</td>
<td>Scale</td>
</tr>
<tr>
<td>-----------------</td>
<td>-----------</td>
<td>-------------</td>
<td>---------------------------</td>
<td>-------</td>
</tr>
<tr>
<td>Sibling relationship questionnaire (SRQ) (Furman &amp; Buhrmester, 1985).</td>
<td>30</td>
<td></td>
<td></td>
<td>5 points, “Hardly at all” to “Extremely much”</td>
</tr>
<tr>
<td>Sibling warmth</td>
<td>21</td>
<td>How much do both you and your sibling share with each other?</td>
<td>Factor score: mean of all subscales below</td>
<td></td>
</tr>
<tr>
<td>Sibling pro-social behaviour</td>
<td>3</td>
<td>How much do both you and your sibling share with each other?</td>
<td>Subscales are mean scores of items relating to that scale</td>
<td></td>
</tr>
<tr>
<td>Sibling affection</td>
<td>3</td>
<td>Some siblings care about each other a lot while other siblings don’t care about each other that much. How much do you and this sibling care about each other?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sibling companionship</td>
<td>3</td>
<td>How much do you and this sibling go places and do things together?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sibling similarity</td>
<td>3</td>
<td>How much do you and this sibling have in common?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sibling intimacy</td>
<td>3</td>
<td>How much do you and this sibling share secrets and private feelings?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Admiration of sibling</td>
<td>3</td>
<td>How much do you look up to and feel proud of this sibling?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Admiration from sibling</td>
<td>3</td>
<td>How much does this sibling admire and respect you?</td>
<td>Factor score: Mean of subscales below</td>
<td></td>
</tr>
<tr>
<td>Sibling conflict</td>
<td>9</td>
<td>How much do you and this sibling argue with each other?</td>
<td>Subscales are mean scores of items relating to that scale</td>
<td></td>
</tr>
<tr>
<td>Sibling quarrelling</td>
<td>3</td>
<td>How much do you and this sibling argue with each other?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sibling antagonism</td>
<td>3</td>
<td>How much do you and this sibling insult and call each other names?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sibling competition</td>
<td>3</td>
<td>How much do you and this sibling compete with each other?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inventory of parent and peer attachment, peer attachment subscale (IPPA) (Armsden &amp; Greenberg, 1987)</td>
<td>25</td>
<td></td>
<td>1-5 “almost never or never true” to “almost always or always true”</td>
<td></td>
</tr>
<tr>
<td>Peer communication</td>
<td>8</td>
<td>When we discuss things, my friends consider my point of view.</td>
<td>Sum of responses on all items</td>
<td></td>
</tr>
<tr>
<td>Peer trust</td>
<td>10</td>
<td>My friends respect my feelings.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Measure (source)</td>
<td>No. Items</td>
<td>Sample item</td>
<td>Calculation of final score</td>
<td>Scale</td>
</tr>
<tr>
<td>------------------------</td>
<td>-----------</td>
<td>-----------------------------------------------------</td>
<td>----------------------------</td>
<td>-------</td>
</tr>
<tr>
<td>Peer alienation</td>
<td>7</td>
<td>I feel alone or apart when I am with my friends.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>


Depression: Centre of Epidemiological Studies, Depression, Children’s version (CES-DC) (Weissman et al., 1980).

The CES-DC consists of 20 items containing statements about a person’s mood and behaviours over the past week, four of these items were reverse scored. The designers of the CES-DC proposed a cut-off total score of 15 which identified 9% of the original sample \((N = 28)\) (aged 6-17) as potentially having problematic low mood (Weissman et al., 1980). This cut-off was supported by Fendrich, Weissman, and Warner (1990) with 220 participants aged between six and 23, they comment the measure is particularly appropriate for those aged 12 and 18. The CES-DC has been evaluated with 13 to 17 year old US psychiatric inpatients \((N = 107)\) and demonstrated good internal consistency (Cronbach’s alpha = .86), test-retest reliability \((r = .69, p < .001)\), and adequate concurrent validity through a correlation of .61 \((p < .001)\) with the ‘Children’s Depression Inventory’ (CDI) (Faulstich, Carey, Ruggiero, Enyart, & Gresham, 1986). A different study, using a non-clinical population aged 9-18 \((N = 1207)\) similarly found a correlation of .58 with the CDI (Doerfler, Felner, Rowlison, Raley, & Evans, 1988). However, this study questioned the use of the recommended cut-off as 48% of their sample had scores above this level. Consequently, in the present study, the CES-DC has been used primarily as a continuous scale, although rates of participants over the cut-off will be discussed.

Rosenberg self-esteem scale (RSE) (Rosenberg, 1965).

The RSE is a well-recognised and validated scale which measures a person’s sense of self-worth. It was designed for use with adolescents although it has been validated in 28 languages across 53 countries including New Zealand with adults. Cronbach’s alpha for New Zealand adults \((N = 272)\) was .86 (Schmitt & Allik, 2005). The RSE has also been used with New Zealand adolescents with good reliability (Cronbach’s alpha = .85) although means were not reported in this study (Paterson, Pryor, & Field, 1995).

Psychological Well-being Scale, short form (Ryff & Keyes, 1995).

The short-form of the psychological wellbeing scale has six subscales reflecting a broad definition of wellbeing. Each subscale is assessed with three questions. The subscales are: autonomy, environmental mastery, personal growth, positive relations with others, purpose in
life, and self-acceptance. Previous studies have demonstrated that when using the short form, internal consistencies for each of the six scales are low (range = .33 to .56) (Ryff & Keyes, 1995) so for this study only the full score will be used. The full-score short-form has demonstrated construct validity through positive correlations with life satisfaction, and a negative correlation with depression among non-institutionalized English speaking adults in the USA (Ryff & Keyes, 1995). A 11-item version of this scale has been used with New Zealand high-school age students with good reliability (Cronbach’s alphas ranging from .86-.90) (O’Connor & Jose, 2012).

The remaining measures in Table 1 assessed dispositional optimism, parental differential treatment, the sibling relationship, and the peer relationship. These were identified through previous research as constructs which may be important for predicting adjustment in adolescent siblings of cancer survivors. The measures used to assess each of these is discussed below.

**Life orientation test (LOT) (Scheier & Carver, 1985).**

The LOT consists of 12 items measuring optimism. Four items are positively worded, four negatively worded and reverse scored, and four are ‘filler’ items which do not contribute to the final mean score assessing optimism. A validation study with 624 undergraduate students gave a 4-week test-retest reliability of .79, and internal consistency of .76 (Cronbach’s alpha) (Scheier & Carver, 1985). Although all initial testing was with undergraduate students, this test has also been used with adolescents, with slightly lower reliability: Among a clinical population aged 15-18 Cronbach’s alpha was .56, (Goodman, Knight, & DuRant, 1997) and among Australian high-school students with a revised scale (the LOT-R) Cronbach’s alpha was .60 (Creed, Patton, & Bartrum, 2002). The current study used the original version of the LOT.² A general optimism scale was chosen, as opposed to an illness-specific measure because this study is directed at siblings of children and young people in remission so their health status is argued to be more stable than those still on active treatment.

² The version of the LOT used was the original version although a revised version (LOT-R) has been available since 1994. This was an oversight on the part of the researcher.
Sibling inventory of differential experience (SIDE) (Daniels & Plomin, 1985b).

The SIDE is a measure that assesses the degree of non-shared experience within families, by asking siblings to compare their environment to that of their sibling(s). The original version of this measure contains three domains: differential sibling interaction, differential parental treatment, and differential peer characteristics. For this study, as in many previous studies, only the differential parental treatment domain was utilised. When used as designed this domain produces four subscales, relative maternal affection, relative paternal affection, relative maternal control and relative paternal control. The aspects of sibling interaction and peer relationships measured by the remaining domains are more effectively captured through different measures, such as the SRQ, and IPPA described in subsequent paragraphs.

The questions in the differential treatment domain require participants to compare themselves with their sibling regarding their treatment from the same parental figure. The SIDE uses a five-point scale from ‘my sibling much more than me’ through ‘both of us about the same’ to ‘me much more than my sibling’.

Some minor adaptations were made to the original scale, as follows: In this study, in order to be inclusive of non-traditional family arrangements, participants were asked to name (by relationship) and rate their two main caregivers rather than being specifically asked about a mother and a father. Additional conglomerate scales of ‘relative parental affection’ and ‘relative parental control’ allowed for the inclusion of parental scores for participants who had a non-traditional family arrangement. Secondly, the original version was designed to measure the average perceived difference in treatment across the time spent living together. However, as this study focuses specifically on siblings of cancer survivors, participants were asked to respond according to difference in behaviour only since their sibling finished treatment.

The SIDE has been validated for use with 12-28 year olds (Daniels & Plomin, 1985a). For a sample of 57 biological siblings, two-week test-retest reliability averaged .80 across domains. Furthermore, when siblings dyads completed the SIDE independently, there was significant agreement on all subscales (p <.05), between -.25 and -.49 for a sample of 149 pairs of siblings. (Note: A negative relationship indicates agreement as while sibling A reports they receive relatively more affection/control than sibling B, sibling B reports they receive relatively less affection/control than sibling A) (Daniels & Plomin, 1985a). In the same validation study average relative scores for the whole sample were very close to 3.0 (my sibling and me about the
same), ranging from $2.98 (SD = .48)$ for differential paternal affection, to $3.09 (SD = .75)$ for differential paternal control.

**Perceived fairness of differential treatment (Kowal et al., 2002).**

Kowal et al’s (2002) fairness scale is attached to the SIDE parental differential treatment scale described above. The fairness scale adds a secondary question to each item on the SIDE asking if treatment was fair or unfair. This question was added because previous researchers have suggested that a greater connection between non-equal parental treatment and psychological effects may be found when children’s understanding of their parents’ behaviour is considered. This secondary question taps into perceptions of equitable treatment, rather than equal treatment, under the supposition that equitable treatment may be more related to socio-emotional wellbeing than equal treatment (Kowal et al., 2002). For example in one study, 74% of the cases of non-equal treatment reported by 11-17 year olds were perceived as fair. Perception of fairness/unfairness was related to global self-worth, and internalizing scales of the child-behaviour checklist (CBCL) when magnitude of unequal treatment was not (Kowal et al., 2002). Fairness responses were divided into the same scales as the SIDE with the addition of a ‘total unfairness’ scale for mothers, fathers, and parents, which totalled responses from each parent across both affection and control.

**Sibling relationship questionnaire (SRQ) (Furman, 1988).**

The full SRQ is a 48 item measure that covers dimensions of the sibling relationship that were identified by 11-13 year olds as primary qualities of their sibling relationships. Sixteen subscales contribute to four factors: Warmth/closeness; Relative power/status; Conflict; and Rivalry. For this study, we used only those sub-scales which contribute to factors of warmth/closeness, and conflict. The rivalry scale was removed because it covers maternal and paternal partiality, which was measured through the SIDE, and relative status/power was removed as previous research shows it is mostly accounted for by relative ages of siblings (older/younger) ($r = .81$), in contrast, age, gender, and relative age did not account for more than 20% of the variance on the other factors (Furman & Buhrmester, 1985). Furman and Buhrmester’s (1985) reliability analysis with 198, 11-13 year old children showed Cronbach’s alpha exceeded .70 for all but one of the 16 scales (sibling competition, part of the conflict
factor), and ten-day test-retest reliability averaged .71 for all the scales (minimum = .58; maximum = .86).

The subscales of sibling warmth are: sibling pro-social behaviour, sibling affection, sibling companionship, sibling similarity, sibling intimacy, admiration of sibling, and admiration from sibling. The subscales of sibling conflict are: sibling quarrelling, sibling competition, and sibling antagonism.

**Inventory of parent and peer attachment, peer attachment subscale (IPPA)**

*(Armsden & Greenberg, 1987)*.

The IPPA consists of a parent and peer scale measuring adolescents’ perceived attachment to parents and peers. For the purposes of this study, only the peer attachment scale was used. The peer attachment scale of the IPPA consists of three subscales: ‘Peer trust’ which measures degree of mutual trust, ‘peer communication’ measuring quality of communication, and ‘peer alienation’ which measures the extent of anger and alienation in relation to peers. In a study using 16-20 year old USA college students each subscale had good internal consistency with Cronbach’s alpha of .91 for the trust subscale, .87 for the communication subscale, and .72 on the alienation subscale *(Armsden & Greenberg, 1987)*. Peer attachment as measured by the IPPA is positively related to self-esteem, life-satisfaction, and coping skills, and negatively associated with depression *(Armsden & Greenberg, 1987)*. In New Zealand, in 1987-1988 the Dunedin multidisciplinary health and development study cohort *(N = 2775)* *(Richards, McGee, Williams, Welch, & Hancox, 2010)* completed a shortened version of the IPPA containing 24 items, 12 on the peer attachment scale, participants were aged 15 at the time. Results showed females had higher peer attachment than males. A 2004 Youth Lifestyle study in New Zealand used the same shortened version of the IPPA 16 years later *(Richards et al., 2010)* and found peer attachment had decreased overall although females *(N = 1385)* still had higher attachment to peers relative to male adolescents.

A scale of family cohesion was also incorporated into the questionnaire; however the results from this section are not being used in the present study.
Procedure

Data collection.

Approval for the study was obtained from the Health and Disability Multi-region Ethics Committee, which reviews national and multi-regional studies in New Zealand\(^3\).

All participants who completed the questionnaire were entered into a draw for one of four $100 vouchers for a store of their choice. Participants were recruited through three charitable organisations: Child-Cancer Foundation, Camp Quality, and CanTeen. Participants and parents saw a participant information sheet (Appendix C) and completed a consent form if aged 16-18, or a parental consent form and an assent form if aged 12-15 (Appendix D). The participant questionnaire and parent questionnaires were either posted, or made available online (Appendices A and B).

*Child cancer foundation (CCF):* CCF is an organisation supporting families of children with cancer through a range of programs and services. From October 2010 to January 2011 CCF advertised the current study project through their quarterly newsletter, and each regional centre was emailed about the study and invited to print an A4 poster displaying information and contact details for the study. Interested participants contacted researchers directly by phone, text, or email, and in return were posted a pack containing the participant information sheets, consent forms and questionnaires plus two self-addressed postage-paid return envelopes for the parent questionnaire and the sibling questionnaire.

*Camp Quality (CQ):* CQ is an organisation which provides camps and recreational events for 6-16 year old child cancer patients, survivors, and occasionally siblings. CQ included a letter describing the research and inviting participation with some of their annual mail-outs sent between December 2010 and January 2011. The letter asked interested participants to contact the research team by post, phone, text, or email, after which they were posted the pack containing questionnaires, participant information sheets, consent/assent forms, and self-addressed postage-paid return envelopes.

---

\(^3\) Reference number: MEC/10/05/046
**Canteen NZ:** CanTeen is an organisation specifically designed for teenagers and young adults (aged 13-24) who are cancer patients, survivors, or siblings. CanTeen identified a list of sibling members aged 13-18 and emailed these members directly in June 2011 with an email containing a link to a copy of the participant information sheet, consent/assent forms, and sibling questionnaire through Survey Monkey Online. Participants were asked to provide their parents’ contact details for completion of the parental questionnaire and parental consent forms where necessary.

Data collection therefore covered a nine month period and some participants may have heard about the study from more than one source. Data gathered was entered into IBM SPSS v.20 as it was returned.

**Missing data.**

Where more than five data points were missing from a participant’s questionnaire, participants were contacted by email and phone to obtain the missing information, however, some participants did not respond to these attempts at contact so further information could not be retrieved. To compensate for missing values where total scores were required, the missing value was predicted by the mean of available values for that case on the same subscale. Missing sections were excluded from analyses involving that section but the participant was included in other analyses. See questionnaire results for a breakdown of specific missing data.

**Checking data.**

Before analysis, every fifth entry (20%) was re-entered and checked for disparities in data entry. Where discrepancies were found between the first and second entry, the original version (e.g. the hardcopy) was consulted, and data corrected accordingly. In sets with any wrongly entered data, the entries immediately before and after were also checked for incorrectly entered data. Frequencies for each item were also checked, to ensure no entries had been made that were not possible (e.g. 33 entered instead of 3).

**Analysis plan.**

Preliminary analyses involved checking assumptions were met for parametric analyses. This included checking for missing values, normality of scales, reliability of scales, and outliers, and correcting for these anomalies where necessary. This was followed by descriptive analyses.
then correlations with measures of psychological adjustment to investigate patterns and relationships predicting positive adaptation. Finally, regressions were conducted to assess the roles of situational/demographic variables, optimism, parental differential treatment, the sibling relationship, and peer relationships in predicting the outcome variables of depression, self-esteem, and wellbeing. The small sample size prevented the inclusion of all variables simultaneously. Therefore, for each measure, rather than including all subscales, the scales which incorporated information from more than one subscale were used in regressions. In this way, the greatest breadth of information was covered, although some specificity was lost.
Chapter Three: Results from the Questionnaire Study

Chapter overview.

This chapter describes the analysis and results from the questionnaire study. This study aims to determine what variables have an impact on psychological wellbeing for the sibling of a child or young person who has completed cancer treatment. The specific aims of the questionnaire study are as follows:

- To explore a range of cognitive, demographic and psychosocial factors that may predict the general wellbeing of adolescents who have a sibling with cancer; and
- To use the data we gather to try and identify ‘at-risk siblings’.

Preliminary analyses

Missing data.

Due to a computer programming error through Survey Monkey, seven participants out of a total of 11 who attempted to do the survey online were unable to complete the questionnaire in full on their first attempt. These participants were contacted and five out of the seven subsequently completed the entire survey. Three of these completed the survey within 48 hours of their original attempt, and the remaining two completed it within two weeks. In three cases the parent questionnaire was never completed despite follow-up attempts. In all three cases these participants were 16-18 years of age so parental consent was not required for their participation. Excluding the missing information described above, there were 16 randomly missing data points from 5208 potential data points (0.3%).

Tests of assumptions for parametric testing.

To determine suitability for parametric analyses, outliers were identified and corrected, and variables were assessed for problematic kurtosis and skewness.

Outliers.

Using Z-scores generated by IBM SPSS 20, outliers were identified by their z-scores, with a cut-off of greater than 2.58 or less than -2.58 applied. This cut-off is equivalent to p<.01 and
identified seven outliers on seven different variables. Each outlier was investigated to check the error was unrelated to incorrect data entry, or other errors in collecting. All outliers were kept in the model, but their influence on the models were reduced by changing their value to the mean +/- 2 standard deviations (Field, 2005). See Appendix E for outliers, and the changes made to them.

**Normality.**

Normality of distributions is assessed by calculating the z-scores for the skewness and kurtosis by dividing the kurtosis and skewness values for each scale by their standard error. A cut off of greater than 3.29 or less than -3.29 (p < .001) is used with small samples to identify variables with problematic skewness or kurtosis (Field, 2005; Tabachnick & Fidell, 2007). Although some variables initially appeared to have non-normal distributions, after initial outliers were changed to the mean +/- 2 standard deviations, all variables had acceptable skewness and kurtosis.

**Reliability.**

Reliability analyses involved calculating Cronbach’s coefficient alpha for each scale. Aron, Aron, and Coups (2006) suggest measures within psychology should have reliability of at least .60. Eight variables in this study had coefficient alphas below .60. Seven of these eight were taken from the parental differential treatment scale. All three affection subscales from the SIDE had co-efficient alphas below .60 (relative maternal affection $\alpha = .58$; relative paternal affection $\alpha = .56$; relative parental affection $\alpha = .54$). Examining the item-total statistics for these affection subscales did not consistently identify any particular item as problematic across scales. Given this lack of pattern there was no theoretical reason to remove any troublesome items from the scale, so Cronbach’s alpha for the affection scales remained slightly low. The remaining four scales with low reliability from the SIDE were from the appended fairness scale: maternal affection unfairness ($\alpha = .55$), maternal control unfairness ($\alpha = .55$), paternal affection unfairness ($\alpha = .26$) and parental affection unfairness ($\alpha = .45$). The item-total statistics did not identify any particular item(s) as repeatedly problematic so reliability as low as .45 was accepted on these scales. This allowed for the inclusion of maternal affection unfairness, maternal control unfairness, and parental affection unfairness. However paternal affection unfairness still had unacceptably low reliability at .26, unimproved by the removal of any item. This variable has
therefore been discarded from the data-set. The low reliability on the retained scales will be considered in terms of applicability and generalisability of the overall results where applicable. The fairness items had a dichotomous response scale, and dichotomous scales tend to produce lower reliabilities which may partially explain these findings (Tabachnick & Fidell, 2007). In the case of paternal affection unfairness, it is theorised that Cronbach’s alpha was so low not only because of a dichotomous scale, but also because of so few endorsements of unfair behaviour of fathers in relation to affection. The mean for this scale is 0.10 which indicates only 10% of the questions about paternal affection fairness were answered with ‘unfair’.

The final variable with low reliability was the sibling antagonism scale from the SRQ with a coefficient alpha of .59. Inspection of the item-total statistics showed this could be improved to .82 by removing one item: “How much are you and this sibling mean to each other?” [emphasis added]. Based on examining participants’ answers to this question, in context of their other answers, it appears a number of participants read this as “how much do you and this sibling mean to each other?” Henceforth, any further mention of the sibling antagonism scale will refer to a revised version which does not contain this item.

**Descriptives.**

Table 2 shows the means, standard deviations, kurtosis, skewness, and Cronbach’s alpha for each variable including original and revised versions of variables where preliminary analyses suggested revision was necessary. In this section central tendency and spread will be described in relation to each scale.

**Psychosocial adjustment.**

Participants on average were ‘a little’ depressed (M = 0.96 [corresponds to a total score of 19.2]; SD = .58). Furthermore, 76% of the sample was above the cut-off score proposed by the test designers. The theoretically possible range on this scale is 0-3 and the current results ranged from .15 to 2.4 suggesting the participants covered close to the full range of measurable mood on this scale, falling short only of the most severe depression levels. Regarding self-esteem, the theoretically possible range is also 0-3 so the mean of 2.06 (SD = 0.54) is close to the centre point and also corresponds closely to the mean response of 272 adults in New Zealand (30.24 on a scale scored 1-4 instead of 0-3 and results of 10 items totalled rather than averaged). Studies with New Zealand adolescents using the RSE have either not reported means or have not used an
### Table 2

Descriptive data and reliability for all measured variables

<table>
<thead>
<tr>
<th>Variable name</th>
<th>N valid</th>
<th>Mean</th>
<th>Standard deviation</th>
<th>Skewness (standard error)</th>
<th>Kurtosis (standard error)</th>
<th>Cronbach’s alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depression</td>
<td>29</td>
<td>.96</td>
<td>.58</td>
<td>.99(.43)</td>
<td>.76(.85)</td>
<td>.90</td>
</tr>
<tr>
<td>Self esteem</td>
<td>30</td>
<td>2.06</td>
<td>.56</td>
<td>-.44(.43)</td>
<td>-.16(.83)</td>
<td>.88</td>
</tr>
<tr>
<td>Wellbeing</td>
<td>30</td>
<td>4.36</td>
<td>.59</td>
<td>-.61(.43)</td>
<td>4.71(.83)</td>
<td>.80</td>
</tr>
<tr>
<td>Sibling antagonism</td>
<td>30</td>
<td>4.39</td>
<td>.49</td>
<td>-.53(.43)</td>
<td>.19(.83)</td>
<td>.80</td>
</tr>
<tr>
<td>Sibling quarrelling</td>
<td>30</td>
<td>2.88</td>
<td>.70</td>
<td>.12(.46)</td>
<td>1.14(.90)</td>
<td>.56</td>
</tr>
<tr>
<td>Relative paternal control</td>
<td>28</td>
<td>2.54</td>
<td>.47</td>
<td>-.46(.44)</td>
<td>1.62(.86)</td>
<td>.58</td>
</tr>
<tr>
<td>Relative maternal affection</td>
<td>28</td>
<td>2.55</td>
<td>.43</td>
<td>-.08(.44)</td>
<td>.34(.86)</td>
<td>.58</td>
</tr>
<tr>
<td>Relative maternal control</td>
<td>28</td>
<td>3.50</td>
<td>.80</td>
<td>-.69(.44)</td>
<td>2.54(.86)</td>
<td>.80</td>
</tr>
<tr>
<td>Relative paternal affection</td>
<td>25</td>
<td>2.69</td>
<td>.39</td>
<td>.61(.42)</td>
<td>1.79(.82)</td>
<td>.54</td>
</tr>
<tr>
<td>Relative parental control</td>
<td>31</td>
<td>3.42</td>
<td>.72</td>
<td>-.26(.42)</td>
<td>1.68(.82)</td>
<td>.80</td>
</tr>
<tr>
<td>Maternal affection unfairness</td>
<td>28</td>
<td>.25</td>
<td>.26</td>
<td>.81(.44)</td>
<td>-.42(.86)</td>
<td>.55</td>
</tr>
<tr>
<td>Maternal control unfairness</td>
<td>28</td>
<td>.38</td>
<td>.33</td>
<td>.52(.44)</td>
<td>-.71(.86)</td>
<td>.55</td>
</tr>
<tr>
<td>Maternal total unfairness</td>
<td>28</td>
<td>.30</td>
<td>.25</td>
<td>.32(.44)</td>
<td>-.11(.86)</td>
<td>.68</td>
</tr>
<tr>
<td>Paternal affection unfairness</td>
<td>25</td>
<td>.10</td>
<td>.15</td>
<td>1.12(.46)</td>
<td>-.28(.90)</td>
<td>.26</td>
</tr>
<tr>
<td>Paternal control unfairness</td>
<td>25</td>
<td>.32</td>
<td>.36</td>
<td>.78(.46)</td>
<td>-.80(.90)</td>
<td>.79</td>
</tr>
<tr>
<td>Paternal total unfairness</td>
<td>25</td>
<td>.20</td>
<td>.22</td>
<td>.86(.46)</td>
<td>-.50(.90)</td>
<td>.76</td>
</tr>
<tr>
<td>Parental affection unfairness</td>
<td>31</td>
<td>.18</td>
<td>.18</td>
<td>.98(.42)</td>
<td>.16(.82)</td>
<td>.45</td>
</tr>
<tr>
<td>Parental control unfairness</td>
<td>31</td>
<td>.35</td>
<td>.32</td>
<td>.51(.42)</td>
<td>-.74(.82)</td>
<td>.68</td>
</tr>
<tr>
<td>Parental total unfairness</td>
<td>31</td>
<td>.25</td>
<td>.22</td>
<td>.56(.42)</td>
<td>-.32(.82)</td>
<td>.74</td>
</tr>
<tr>
<td>Sibling warmth</td>
<td>29</td>
<td>3.29</td>
<td>.78</td>
<td>.01(.43)</td>
<td>-.65(.85)</td>
<td>.95</td>
</tr>
<tr>
<td>Sibling conflict</td>
<td>29</td>
<td>2.89</td>
<td>.87</td>
<td>.23(.43)</td>
<td>-.44(.85)</td>
<td>.89</td>
</tr>
<tr>
<td>Sibling pro-social behaviour</td>
<td>29</td>
<td>3.06</td>
<td>.91</td>
<td>-.18(.43)</td>
<td>-.29(.85)</td>
<td>.82</td>
</tr>
<tr>
<td>Sibling affection</td>
<td>29</td>
<td>3.94</td>
<td>.74</td>
<td>-.37(.43)</td>
<td>-.50(.85)</td>
<td>.77</td>
</tr>
<tr>
<td>Sibling companionship</td>
<td>29</td>
<td>3.20</td>
<td>1.09</td>
<td>-.05(.43)</td>
<td>-1.01(.85)</td>
<td>.85</td>
</tr>
<tr>
<td>Sibling similarity</td>
<td>29</td>
<td>3.14</td>
<td>.92</td>
<td>-.16(.43)</td>
<td>.02(.85)</td>
<td>.91</td>
</tr>
<tr>
<td>Sibling intimacy</td>
<td>29</td>
<td>2.41</td>
<td>1.23</td>
<td>.59(.43)</td>
<td>-.83(.85)</td>
<td>.93</td>
</tr>
<tr>
<td>Admiration of sibling</td>
<td>29</td>
<td>3.86</td>
<td>.94</td>
<td>-.47(.43)</td>
<td>-.74(.85)</td>
<td>.92</td>
</tr>
<tr>
<td>Admiration from sibling</td>
<td>29</td>
<td>3.44</td>
<td>1.02</td>
<td>.08(.43)</td>
<td>-.22(.85)</td>
<td>.92</td>
</tr>
<tr>
<td>Sibling quarrelling</td>
<td>29</td>
<td>3.06</td>
<td>.95</td>
<td>.24(.43)</td>
<td>-1.02(.85)</td>
<td>.87</td>
</tr>
<tr>
<td>Sibling antagonism</td>
<td>29</td>
<td>3.06</td>
<td>.96</td>
<td>.08(.43)</td>
<td>-.88(.85)</td>
<td>.59</td>
</tr>
<tr>
<td>Item 14 removed</td>
<td>29</td>
<td>2.86</td>
<td>1.19</td>
<td>.08(.43)</td>
<td>-1.0(.85)</td>
<td>.82</td>
</tr>
<tr>
<td>Sibling competition</td>
<td>29</td>
<td>2.56</td>
<td>1.12</td>
<td>.24(.43)</td>
<td>-.82(.85)</td>
<td>.90</td>
</tr>
<tr>
<td>Peer communication</td>
<td>30</td>
<td>26.48</td>
<td>7.29</td>
<td>-.38(.43)</td>
<td>-.46(.83)</td>
<td>.89</td>
</tr>
<tr>
<td>Peer trust</td>
<td>30</td>
<td>39.78</td>
<td>9.41</td>
<td>-1.64(.43)</td>
<td>2.85(.83)</td>
<td>.95</td>
</tr>
<tr>
<td>Peer alienation</td>
<td>30</td>
<td>18.43</td>
<td>4.75</td>
<td>.24(.43)</td>
<td>-.21(.83)</td>
<td>.62</td>
</tr>
</tbody>
</table>

Note. Italics indicate statistics are from a variable adapted in some way

*This scale is not used for any subsequent data analyses due to low reliability*
equivalent scale for response, however a norming study with 2,108 Canadian high-school students reported a scale mean 31.36 (standard deviation 5.13), which corresponds to a mean of 2.14 (SD = .51). Together these findings suggest that based on our scoring method, the present sample was well within the normal range. Normative or comparative data is not available for the wellbeing scale, however participants on average ‘slightly agreed’ to positively worded items such as “For me, life has been a continuous process of learning, changing, and growth” (M = 4.39; SD = 0.49).

Optimism.

The mean optimism score was slightly above the midpoint of ‘neutral’ on positively worded items such as “in uncertain times, I usually expect the best” (M = 2.33; SD = .43). Participants’ scores ranged from 1.40 to 3.25. In the validation study of the LOT which took place across two universities in the United States of America, the mean total score of 357 undergraduate men was 21.03 (SD 4.56), the mean total score of 267 undergraduate women was 21.41 (SD 5.22) (Scheier & Carver, 1985) these correspond to mean-scores of 2.63 (SD = .57) and 2.68 (SD = .65). Therefore, the population in the present study had slightly lower rates of optimism than a USA undergraduate population.


The means from the SIDE show that overall, participants noted slight dis-favouring behaviour from their parents in comparison to their sibling who had cancer. That is, they reported they were slightly more controlled (Maternal control M = 3.54, SD = 0.71; Paternal control M = 3.27, SD = 0.70; Parental control M = 3.44, SD = 0.67) and received slightly less affection (Maternal affection M = 2.55, SD = 0.43; Paternal affection M = 2.84, SD = 0.43; Parental affection = 2.68, SD 0.36) than their sibling. Treatment was close to equal in most cases; when directionality of differential treatment was removed to give an absolute score, all means were below 1. Regarding fairness, trends indicated fathers were generally reported as being fairer than mothers, and all parents were seen as more fair in their affection than their control. Overall, 52% of instances of unequal treatment were seen as fair, and 48% as unfair. When affection favoured the participant, this was seen as fair 73% of the time, compared to 58% of the time when affection favoured the patient. Regarding control, when participants were more controlled
than their siblings, this was seen as fair only 33% of the time, compared to 63% of the time when patients were controlled more often than the participant.

**Sibling relationships.**

With respect to siblings, participants reported ‘somewhat’ warm relationships and ‘somewhat’ conflictual relationships. Most subscales of these factor scores also had means near the midpoint of ‘somewhat’ (3.0). However the subscales of sibling affection and sibling admiration showed slightly higher means and narrower standard deviations than other subscales. This indicates participants are in agreement in feeling ‘very much’ admiration of, and affection for their sibling, shown through items such as “How much do you look up to and feel proud of this sibling?” In contrast, mean sibling intimacy was comparatively low with the widest standard deviation of the sibling measures (M = 2.41; SD = 1.23) indicating participants vary more widely in the degree of perceived intimacy in the relationship although on average they reported ‘not too much’ intimacy (e.g. ‘How much do you and this sibling share secrets and private feelings?’).

**Peer relationships.**

Participants were very varied in their attachment to their peers, means indicated an average response of ‘sometimes true’ to positively worded questions about peer communication, an average response of ‘often true’ to positively worded questions about peer trust, and an average response between ‘seldom true’ and ‘sometimes true’ for questions asking about alienation. However, the ranges suggest a wide range in response, for example, for the peer trust subscale, the minimum and maximum scores represent the two poles of the scale (10 and 50). There are no norms available to compare these findings to as most previous studies have either been completed with a very different population, have not reported means, or have adapted the scale in some way as to make direct comparisons impossible.

**Correlations**

Correlations were conducted and Pearson product moment coefficients calculated for every variable with the outcome measures of depression, self-esteem, and well-being. These are displayed below in Table 3 with significant correlations discussed below. In addition to those described below, all three outcome variables were highly correlated with each other in the expected directions, with correlation coefficients ranging from .65 to .84.
Table 3
Correlations of variables with depression, self-esteem and wellbeing

<table>
<thead>
<tr>
<th></th>
<th>Depression</th>
<th>Self-esteem</th>
<th>Wellbeing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depression</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-esteem</td>
<td>-.65**</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wellbeing</td>
<td>-.80**</td>
<td>.84**</td>
<td></td>
</tr>
<tr>
<td>Participant age</td>
<td>.03</td>
<td>.01</td>
<td>.06</td>
</tr>
<tr>
<td>Gender (0=male, 1=female)</td>
<td>.24</td>
<td>-.22</td>
<td>-.09</td>
</tr>
<tr>
<td>Family size (0=small, 1=large)</td>
<td>-.40*</td>
<td>.32</td>
<td>.37*</td>
</tr>
<tr>
<td>Time since treatment</td>
<td>-.08</td>
<td>.03</td>
<td>.06</td>
</tr>
<tr>
<td>Time since diagnosis</td>
<td>-.04</td>
<td>.15</td>
<td>.12</td>
</tr>
<tr>
<td>Time on treatment</td>
<td>.08</td>
<td>.18</td>
<td>.08</td>
</tr>
<tr>
<td>Optimism</td>
<td>-.62**</td>
<td>.74*</td>
<td>.75**</td>
</tr>
<tr>
<td>Parental differential treatment</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relative maternal affection</td>
<td>-.44*</td>
<td>.14</td>
<td>.20</td>
</tr>
<tr>
<td>Relative maternal control</td>
<td>.08</td>
<td>-.09</td>
<td>-.19</td>
</tr>
<tr>
<td>Relative paternal affection</td>
<td>.03</td>
<td>-.06</td>
<td>-.10</td>
</tr>
<tr>
<td>Relative paternal control</td>
<td>.14</td>
<td>-.03</td>
<td>-.06</td>
</tr>
<tr>
<td>Relative parental affection</td>
<td>-.46*</td>
<td>.23</td>
<td>.29</td>
</tr>
<tr>
<td>Relative parental control</td>
<td>.15</td>
<td>-.14</td>
<td>-.25</td>
</tr>
<tr>
<td>Maternal affection unfairness</td>
<td>.25</td>
<td>-.07</td>
<td>-.18</td>
</tr>
<tr>
<td>Maternal control unfairness</td>
<td>.06</td>
<td>.09</td>
<td>-.10</td>
</tr>
<tr>
<td>Total maternal unfairness</td>
<td>.17</td>
<td>.02</td>
<td>-.16</td>
</tr>
<tr>
<td>Paternal control unfairness</td>
<td>.40</td>
<td>-.04</td>
<td>-.18</td>
</tr>
<tr>
<td>Total parental unfairness</td>
<td>.43*</td>
<td>-.08</td>
<td>-.18</td>
</tr>
<tr>
<td>Parental affection unfairness</td>
<td>.40*</td>
<td>-.20</td>
<td>-.32</td>
</tr>
<tr>
<td>Parental control unfairness</td>
<td>.20</td>
<td>.00</td>
<td>-.20</td>
</tr>
<tr>
<td>Total parental unfairness</td>
<td>.31</td>
<td>-.09</td>
<td>-.27</td>
</tr>
<tr>
<td>Sibling relationship</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sibling warmth</td>
<td>.28</td>
<td>-.44*</td>
<td>-.44*</td>
</tr>
<tr>
<td>Sibling conflict</td>
<td>-.00</td>
<td>.07</td>
<td>-.06</td>
</tr>
<tr>
<td>Sibling pro-social behaviour</td>
<td>.27</td>
<td>-.39*</td>
<td>-.38*</td>
</tr>
<tr>
<td>Sibling affection</td>
<td>.27</td>
<td>-.46*</td>
<td>-.34</td>
</tr>
<tr>
<td>Sibling companionship</td>
<td>.35</td>
<td>-.44*</td>
<td>-.47*</td>
</tr>
<tr>
<td>Sibling similarity</td>
<td>.12</td>
<td>-.22</td>
<td>-.29</td>
</tr>
<tr>
<td>Sibling intimacy</td>
<td>.22</td>
<td>-.36</td>
<td>-.36</td>
</tr>
<tr>
<td>Admiration of sibling</td>
<td>.17</td>
<td>-.26</td>
<td>-.19</td>
</tr>
<tr>
<td>Admiration from sibling</td>
<td>.20</td>
<td>-.32</td>
<td>-.42*</td>
</tr>
<tr>
<td>Sibling antagonism</td>
<td>.08</td>
<td>.15</td>
<td>-.00</td>
</tr>
<tr>
<td>Sibling competition</td>
<td>-.02</td>
<td>.02</td>
<td>-.09</td>
</tr>
<tr>
<td>Sibling quarrelling</td>
<td>.01</td>
<td>.10</td>
<td>-.00</td>
</tr>
<tr>
<td>Peer relationship</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Peer communication</td>
<td>.09</td>
<td>-.05</td>
<td>-.10</td>
</tr>
<tr>
<td>Peer trust</td>
<td>-.21</td>
<td>.23</td>
<td>.18</td>
</tr>
<tr>
<td>Peer alienation</td>
<td>-.53**</td>
<td>-.35</td>
<td>-.30</td>
</tr>
</tbody>
</table>

* these variables have low reliabilities, Cronbach’s Alphas between .45 and .6
Depression.

Higher depression scores were found in participants from smaller families \( (r(29) = -0.40, p = 0.030) \) and those who reported more peer alienation \( (r(29) = -0.53, p = 0.003) \) and lower optimism \( (r(29) = -0.62, p < 0.001) \). Higher depression was also reported by participants who reported receiving less affection from their mothers or both parents relative to their brother or sister who had cancer (relative maternal affection, \( r(26) = -0.44, p = 0.025 \); and relative parental affection \( r(29) = -0.46, p = 0.012 \)). Note however that the correlation between depression and relative parental affection is likely driven by the underlying correlation between depression and relative maternal affection, as relative paternal affection had a very low correlation with depression \( (r(23) = 0.03, p = 0.89) \). Finally, greater unfairness in paternal behaviour, and in parental affection was associated with higher reporting of depressive symptoms (total parental unfairness, \( r(23) = 0.43, p = 0.042 \); parental affection unfairness, \( r(29) = 0.40, p = 0.030 \)). Caution must be taken in interpreting the results relating to the measures of parental differential treatment as the measures of relative affection had low reliability (relative maternal affection \( \alpha = 0.58 \); relative paternal affection \( \alpha = 0.56 \); relative parental affection \( \alpha = 0.54 \)), as did parental affection unfairness \( (\alpha = 0.45) \). Further studies will need to replicate these results before generalising these findings.

Self-esteem.

Higher self-esteem was strongly associated with higher reports of optimism \( (r(30) = 0.74, p < 0.001) \) and moderately associated with reports of low sibling warmth \( (r(29) = -0.44, p = 0.018) \). At a subscale level, higher self-esteem occurred in conjunction with reports of lower sibling pro-social behaviour \( (r(29) = -0.39, p = 0.036) \), lower sibling affection \( (r(29) = -0.46, p = 0.013) \), and lower sibling companionship \( (r(29) = -0.44, p = 0.017) \). Self-esteem was unrelated to any demographic variables, general family features, or peer relationship variables.

Wellbeing.

Higher overall wellbeing was associated with being from a bigger family \( (r(30) = 0.37, p = 0.043) \) and having higher optimism \( (r(30) = 0.75, p < 0.001) \). As with self-esteem, higher wellbeing was associated with lower reported levels of sibling warmth \( (r(29) = -0.44, p = 0.017) \), particularly lower sibling pro-social behaviour \( (r(29) = -0.38, p = 0.044) \), more distant sibling companionship \( (r(29) = -0.47, p = 0.011) \), and lower admiration from sibling \( (r(29) = -0.42, p = 0.023) \). Chapter five
will discuss the direction of this relationship, in which more warmth is associated with arguably poorer outcomes of lower wellbeing and lower self-esteem.

**Regressions analysis**

Multiple linear regression was used to investigate how a range of demographic, parental, sibling, and peer factors related to depression, self-esteem, and wellbeing in adolescent siblings of cancer survivors. Power calculations made using G*Power 3.1.6 indicated that given the small sample size, no more than three predictors could be entered into a model at a time in order to detect a significant $R^2$ deviation from zero, or $R$-squared increase, at the .05 level with a minimum effect size of .35 while maintaining 70% power. Previous research with siblings of children of cancer has not generated specific hypothesis for testing, so the analyses completed were explorative, aimed at identifying potential relationships suitable for more in-depth investigation in future research.

The regressions analyses were conducted in three stages. In the first stage, outcome variables (depression, self-esteem, and wellbeing) were regressed against three demographic variables, namely age, gender and family size. Age and gender were selected for inclusion in this regression because they are the most commonly reported on demographic factors in previous research on siblings of children with cancer (Alderfer et al., 2009). Family size was included as it was the only demographic variable which correlated with any of the measures of psychological adjustment. Furthermore, all three of these variables were recorded from the sibling questionnaire. Illness characteristics, time since diagnosis and other variables considered for inclusion were from the parent questionnaire, which had fewer complete responses. Using these variables would have decreased the power to detect significant differences to below 70 percent.

In the second stage, outcomes were predicted by variables grouped to represent different relationships of influence. Three regressions were conducted for each outcome, covering the parent relationship, the sibling relationship, and the peer relationship. As mentioned above, variables for inclusion in regressions were chosen to maximise the breadth covered in each regression. For the parental relationship, this meant scores corresponding to both parents were prioritised over scores relating either to mothers or fathers, and total unfairness was prioritised over unfairness of control or unfairness of affection. For the sibling relationship, this meant factor scores of sibling warmth and sibling conflict were included, but the subscales which made
up the factor scores were not included. The peer relationship measure only produced three subscales, so all three were included in final regressions.

In the third stage of regression analysis, the regressions from the second set were repeated, but with optimism entered as a fixed predictor. Optimism was included as theory would predict it to be strongly related to all three outcome variables, this was supported by the highly significant correlations seen between optimism and all three outcome variables (see Table 3).

For each regression, assumptions of independence of errors, multicollinearity, heteroscedasticity, linearity, and normality were checked with all regressions meeting these assumptions. Furthermore, case-wise diagnostics were examined to identify extreme levels of leverage, discrepancy, and influence. Assumptions were met for 85% of regressions; the remaining 15% had cases with high leverage (Cook’s distance greater than 1). Where applicable more detail is given below.

Predicting psychosocial adjustment from demographic variables.

As stated above, the first set of regressions examined the associations between the age of participant, gender of participant (male coded as 0, female as 1), and family size on the three outcome variables. Family size was a categorical variable coded ‘0’ for families with only two children (the participant, and the cancer survivor), and ‘1’ for families with three or more children.

The results of these linear regressions suggest larger family sizes may be protective against depression (see Table 4) but not self-esteem or wellbeing. Note, however, that overall, none of the models exploring the associations between demographic factors and outcome variables were statistically significant (p<.05) (All non-significant models are available on request).

Table 4
Hierarchical regression predicting depression from demographic factors (N = 29)

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>SE(B)</th>
<th>β</th>
<th>R²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 1</td>
<td></td>
<td></td>
<td></td>
<td>.23</td>
</tr>
<tr>
<td>Constant</td>
<td>.55</td>
<td>.87</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family size</td>
<td>-.51</td>
<td>.21</td>
<td>-.43*</td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>.04</td>
<td>.06</td>
<td>.11</td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td>.29</td>
<td>.21</td>
<td>.24</td>
<td></td>
</tr>
</tbody>
</table>

Note. F(3, 25) = 2.53 p = .080
Adjusted R² = .141
Power = .7 to detect R² change (ES = .35, α=.05)
* = p < .05, ** = p < .01, *** = p < .001
Predicting psychosocial adjustment from grouped variables.

The second stage of regressions used grouped variables (parental, sibling, and peer relationship factors) to predict depression, self-esteem, and wellbeing. This involved nine regressions. Of these nine, only two models were significant, and a further two approached significance. Firstly, depression was significantly predicted by peer relationship factors (see Table 5), and secondly, wellbeing was significantly predicted by the sibling relationship (see Table 7). The regression predicting self-esteem from the sibling relationship approached significance (see Table 8), as did the regression predicting depression from parental differential treatment (see Table 9). These regressions are discussed in more detail below.

Table 5 shows the linear regression of depression being predicted by the peer relationship. In this model, peer alienation was the only predictor that reached significance. However, analysis of case-wise diagnostics for this test identified one case with extremely high leverage, a Cook’s distance of 1.26. This case was therefore removed from the analysis and the regression repeated, this revised version is shown in Table 6. With this case removed, the regression equation accounts for more variance with an increased $R^2$, adjusted-$R^2$ value, and F-statistic. The same basic pattern is evident across both versions of the regression; that peer alienation is the strongest and the only significant predictor of depression with increases in alienation associated with increases in depression. Table 6 shows this regression produced an adjusted $R^2$ of .54, suggesting over half of the variation in depression scores among these participants could be accounted for by variations in peer relationships.

Table 5

**Hierarchical regression predicting depression from peer relationship factors (N = 29)**

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>SE(B)</th>
<th>$\beta$</th>
<th>$R^2$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 1</td>
<td></td>
<td></td>
<td></td>
<td>.35*</td>
</tr>
<tr>
<td>Constant</td>
<td>-.26</td>
<td>.80</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Peer communication</td>
<td>.03</td>
<td>.02</td>
<td>.38</td>
<td></td>
</tr>
<tr>
<td>Peer trust</td>
<td>-.02</td>
<td>.02</td>
<td>-.25</td>
<td></td>
</tr>
<tr>
<td>Peer alienation</td>
<td>.06</td>
<td>.02</td>
<td>.50*</td>
<td></td>
</tr>
</tbody>
</table>

*Note. $F(3, 25) = 4.43$ p = .012  
Adjusted $R^2 = .27$  
Power = .7 to detect $R^2$ change (ES = .35, $\alpha$=.05)  
* = $p < .05$, ** = $p < .01$, *** = $p < .001$
Table 6
Hierarchical regression predicting depression from peer relationship factors with one case excluded (N = 28)

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>SE(B)</th>
<th>β</th>
<th>R²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 1</td>
<td></td>
<td></td>
<td></td>
<td>.59***</td>
</tr>
<tr>
<td>Constant</td>
<td>-.26</td>
<td>.63</td>
<td>.20</td>
<td>.54</td>
</tr>
<tr>
<td>Peer communication</td>
<td>.02</td>
<td>.02</td>
<td>.20</td>
<td></td>
</tr>
<tr>
<td>Peer trust</td>
<td>-.02</td>
<td>.02</td>
<td>-.26</td>
<td></td>
</tr>
<tr>
<td>Peer alienation</td>
<td>.09</td>
<td>.02</td>
<td>.67***</td>
<td></td>
</tr>
</tbody>
</table>

Note. F(3, 24) = 11.54 p < .001
Adjusted R² = .54
Power = .7 to detect R² change (ES = .35, α=.05)
* = p < .05, ** = p < .01, *** = p < .001

Table 7 displays the statistically significant regression model predicting wellbeing from sibling conflict and sibling warmth. The R² value suggests that 23% of the variance in participants’ responses on the wellbeing scale was predicted by the sibling relationship. Most of this variance was accounted for by sibling warmth, as sibling conflict was not a significant predictor of variance. The negative relationship suggests that as relationships become warmer, the wellbeing of siblings decreases. This is the same pattern as found in the correlations and will be discussed in Chapter five. The same variables predicting self-esteem approached significance (p=.062) as a model (see Table 8), with sibling warmth a significant predictor.

Table 7
Hierarchical regression predicting wellbeing from sibling relationship factors (N = 29)

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>SE(B)</th>
<th>β</th>
<th>R²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 1</td>
<td></td>
<td></td>
<td></td>
<td>.23</td>
</tr>
<tr>
<td>Constant</td>
<td>5.80</td>
<td>.56</td>
<td>-.50**</td>
<td>.17</td>
</tr>
<tr>
<td>Sibling warmth</td>
<td>-.32</td>
<td>.12</td>
<td>-.21</td>
<td></td>
</tr>
<tr>
<td>Sibling conflict</td>
<td>-.12</td>
<td>.10</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note. F(2, 26) = 3.9 p = .032
Adjusted R² = .17
Power = .8 to detect R² change (ES = .35, α=.05)
* = p < .05, ** = p < .01, *** = p < .001
Table 8
Hierarchical regression predicting self-esteem from sibling relationship factors (N = 29)

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>SE(B)</th>
<th>β</th>
<th>R²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Constant</td>
<td>3.26</td>
<td>.65</td>
<td></td>
<td>.19</td>
</tr>
<tr>
<td>Sibling warmth</td>
<td>-.33</td>
<td>.14</td>
<td>-.45*</td>
<td></td>
</tr>
<tr>
<td>Sibling conflict</td>
<td>-.04</td>
<td>.12</td>
<td>-.06</td>
<td></td>
</tr>
</tbody>
</table>

Note. F(2, 26) = 3.10 p = .062
Adjusted R² = .13
Power = .8 to detect R² change (ES = .35, α=.05)
* = p < .05, ** = p < .01, *** = p < .001

Table 9 displays the regression predicting depression from relative parental affection, relative parental control, and total parental unfairness. This model did not reach significance (p = .069) although relative parental affection reached significance alone as a predictor. Caution is required in interpreting this regression as relative parental affection was identified as a scale with low reliability (α = .54).

Table 9
Hierarchical regression predicting depression from parental differential treatment (N = 29)

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>SE(B)</th>
<th>β</th>
<th>R²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Constant</td>
<td>3.04</td>
<td>1.10</td>
<td></td>
<td>.24</td>
</tr>
<tr>
<td>Relative parental affection</td>
<td>-.64</td>
<td>-.30</td>
<td>-.42*</td>
<td></td>
</tr>
<tr>
<td>Relative parental control</td>
<td>-.15</td>
<td>.20</td>
<td>-.18</td>
<td></td>
</tr>
<tr>
<td>Total parental unfairness</td>
<td>.64</td>
<td>.62</td>
<td>.25</td>
<td></td>
</tr>
</tbody>
</table>

Note. F(3, 25) = 2.67 p = .069
Adjusted R² = .15
Power = .7 to detect R² change (ES = .35, α=.05)
* = p < .05, ** = p < .01, *** = p < .001

Predicting outcome variables from grouped variables with optimism as a fixed predictor.

In stage three, optimism was included as an additional fixed predictor in all the regressions that were calculated in stage two. All the resulting regressions from this procedure reached significance, with optimism a significant predictor in all models. However, only three of these
nine models had any significant predictors after controlling for optimism. These models were similar to those found without optimism: depression was predicted by optimism and the peer relationship, wellbeing was predicted by optimism and the sibling relationship, and depression was predicted by optimism and parental differential treatment. These three regressions are discussed below.

_Depression predicted by optimism and the peer relationship._

Optimism significantly predicted 39% of variance in depression scores in the first part of this model. However, adding variables from the peer attachment measure significantly improved this model (p = .036) to account for a further 18% of variance. As in the corresponding regression from stage two, one item had an intolerably high Cook’s distance (1.13). Table 11 shows the same regression after this item was removed. In the second model, optimism initially accounts for 40% of the variance in depression scores, but the addition of peer trust, peer communication, and peer alienation increases this by 33% to account for 73% of variance in depression scores (68% adjusted). In both versions, peer alienation is the only significant predictor after optimism, and an increase in alienation is associated with an increase in depression.

### Table 10
_Hierarchical regression predicting depression from optimism and peer relationship factors_

(N = 29)

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>SE(B)</th>
<th>β</th>
<th>R²</th>
<th>ΔR²</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Step 1</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>.39***</td>
</tr>
<tr>
<td>Constant</td>
<td>2.95</td>
<td>.49</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Optimism</td>
<td>-.84</td>
<td>.20</td>
<td>-.62</td>
<td>- .62***</td>
<td></td>
</tr>
<tr>
<td><strong>Step 2</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>.18*</td>
</tr>
<tr>
<td>Constant</td>
<td>1.40</td>
<td>.82</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Optimism</td>
<td>-.67</td>
<td>.19</td>
<td>-.50</td>
<td>-.50**</td>
<td></td>
</tr>
<tr>
<td>Peer communication</td>
<td>.02</td>
<td>.02</td>
<td>.28</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Peer trust</td>
<td>-.01</td>
<td>.02</td>
<td>-.12</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Peer alienation</td>
<td>.05</td>
<td>.02</td>
<td>.40</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Note.* F(1, 27) for Step 1 = 17.18***; F(4, 24) for Step 2 = 7.93***

Adjusted R² for Step 1 = .37, Adjusted R² for step 2 = .50

Power = .7 to detect R² increase (ES = .35, α=.05)

*= p < .05, ** = p < .01, *** = p < .001
**Table 11**
Hierarchical regression predicting depression from optimism and peer relationship factors without an influential case (N = 28)

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>SE(B)</th>
<th>β</th>
<th>R²</th>
<th>ΔR²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Constant</td>
<td>2.93</td>
<td>.48</td>
<td></td>
<td>.40***</td>
<td></td>
</tr>
<tr>
<td>Optimism</td>
<td>-.83</td>
<td>.20</td>
<td>-.63***</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Step 2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>.33***</td>
</tr>
<tr>
<td>Constant</td>
<td>1.03</td>
<td>.65</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Optimism</td>
<td>-.53</td>
<td>.16</td>
<td>-.40**</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Peer communication</td>
<td>.01</td>
<td>.01</td>
<td>.15</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Peer trust</td>
<td>-.01</td>
<td>.01</td>
<td>-.16</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Peer alienation</td>
<td>.07</td>
<td>.02</td>
<td>.56***</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Note. F(1, 26) for Step 1 = 17.00***; F(4, 23) for Step 2 = 15.32***
Adjusted R² for Step 1 = .37, Adjusted R² for step 2 = .68
Power = .7 to detect R² increase (ES = .35, α=.05)
* = p < .05, ** = p < .01, *** = p < .001

Wellbeing predicted by optimism and the sibling relationship.

The model predicting wellbeing from optimism and the sibling relationship reached significance overall, although the second step did not add significantly more predictive value to optimism alone (p=.086) (see Table 12). Within the second step, however, sibling warmth was a significant predictor even after controlling for optimism (p = .030), contributing to the overall improvement of the model.

**Table 12**
Hierarchical regression predicting wellbeing from sibling factors (N = 29)

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>SE(B)</th>
<th>β</th>
<th>R²</th>
<th>ΔR²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>.58***</td>
</tr>
<tr>
<td>Constant</td>
<td>2.29</td>
<td>.35</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Optimism</td>
<td>.90</td>
<td>.15</td>
<td>.76***</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Step 2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>.08$</td>
</tr>
<tr>
<td>Constant</td>
<td>3.23</td>
<td>.60</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Optimism</td>
<td>.80</td>
<td>.15</td>
<td>.68***</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sibling warmth</td>
<td>-.19</td>
<td>.08</td>
<td>-.30*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sibling conflict</td>
<td>-.04</td>
<td>.07</td>
<td>-.06</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Note. F(1, 27) for Step 1 = 37.36***; F(2, 25) for Step 2 = 15.84***
Adjusted R² for Step 1 = .57, Adjusted R² for step 2 = .61
Power = .7 to detect R² increase (ES = .35, α=.05)
* = p < .05, ** = p < .01, *** = p < .001, $ = p = .086
Depression predicted by optimism and parental differential treatment.

Table 13 displays the model of depression being predicted by relative parental affection, relative parental control, and total parental unfairness. In this model, optimism initially accounted for 39% of the variance in participants’ depression ratings. The addition of the three parental differential treatment variables significantly improved the predictive power of this model, and increased the variance accounted for by 20% to a total of 59% (adjusted 52%). In the second step of this model, relative parental unfairness reached significance as a predictor (p = .039) and both relative parental affection and relative parental control approached significance (p = .054 and .056 respectively) suggesting all three variables played a part in increasing the predictive power of the model. However, it is important to note that relative parental affection is a scale identified as having somewhat low reliability (α = .54). Furthermore, in this regression, the relationship between depression and both relative parental affection and relative parental control is negative. However, when these variables were correlated with depression, they produced results in the opposite directions (see Table 3), although the correlation between relative parental control and depression was non-significant. This will be discussed in Chapter 5.

Table 13
Hierarchical regression predicting depression from optimism and parental factors (N = 29)

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>SE(B)</th>
<th>β</th>
<th>( R^2 )</th>
<th>( \Delta R^2 )</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Constant</td>
<td>2.95</td>
<td>.49</td>
<td>.49</td>
<td>.39***</td>
<td></td>
</tr>
<tr>
<td>Optimism</td>
<td>-.84</td>
<td>.20</td>
<td>-.62**</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Step 2</td>
<td></td>
<td></td>
<td></td>
<td>.20*</td>
<td></td>
</tr>
<tr>
<td>Constant</td>
<td>4.97</td>
<td>.94</td>
<td>.94</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Optimism</td>
<td>-.84</td>
<td>.19</td>
<td>-.62**</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relative parental affection</td>
<td>-.46</td>
<td>.23</td>
<td>-.30$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relative parental control</td>
<td>-.31</td>
<td>.15</td>
<td>-.37#</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parental unfairness</td>
<td>.99</td>
<td>.48</td>
<td>.38*</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note. \( F(1, 27) \) for Step 1 = 17.18***; \( F(4, 24) \) for Step 2 = 8.53***
Adjusted \( R^2 \) for Step 1 = .37, Adjusted \( R^2 \) for step 2 = .52
Power = .7 to detect \( R^2 \) increase (ES = .35, α=.05)
* = p < .05, ** = p < .01, *** = p < .001, $ = p = .054, # = p = .056
**Questionnaire study summary**

This study aimed to explore psychosocial adaptation of siblings of child cancer survivors in the context of their coping style and relationships with parents, sibling, and friends. Thirty one siblings of cancer survivors, aged 12-18 completed questionnaires assessing psychosocial adjustment (depression, self-esteem, and wellbeing), optimism, parental differential treatment, family cohesion, the sibling relationship, and peer relationships. The results presented above were produced using descriptive statistics, correlations, and regressions. The main result from the descriptive results was that 76% of participants were above the cut-off score of the CES-DC meaning they reported levels of depressive symptoms that indicate probable mood problems. A main finding from the correlation analyses were that family size was the only significant demographic covariate of any adjustment measures. Participants from smaller families (two children) reported significantly higher wellbeing and lower depression than participants from larger families (three or more children). Furthermore, regression analyses identified a number of significant predictors of depression, self-esteem, and wellbeing. Firstly, when optimism was included in regressions it was a significant predictor of all three measures of psychological adjustment. However the same patterns of relationships remained whether or not optimism was included as a fixed predictor. Peer alienation accounted for a significant proportion of the variance in depression scores both before and after the inclusion of optimism as a predictor. Parental differential treatment factors also accounted for a significant proportion of variance in depression scores, with even more variance accounted for after optimism was included as a fixed predictor.

Finally, sibling warmth was a significant predictor of wellbeing and self-esteem in the second stage of regression (without optimism), however, after controlling for optimism in the third stage, sibling warmth remained a significant predictor of wellbeing, but ceased to have a significant influence on self-esteem. The direction of the findings regarding sibling warmth was somewhat surprising and will be discussed in Chapter five.

Chapter Five ‘Discussion’ will discuss and interpret all these results in the context of the existing literature and the results of the interview study which is described in the following chapter.
Chapter Four: Method and Results of the Interview Study

Chapter overview.

This chapter presents the methods and results of the interview study. Firstly, the method of the study is presented, incorporating participants and the method of identifying participants, a brief description of the interview schedule, and the method of analysis used. Secondly, the results of the thematic analysis are presented. Each of the six themes are presented, including subthemes.

Participants and participant recruitment

Participants who completed the questionnaire study described in the previous chapters were asked at the conclusion of the questionnaire if they were willing to take part in a follow-up face to face interview. This process identified 22 willing interview participants. The sample of 10 participants was selected to give the most representative sample on the basis of gender, age, and depression score. The final participant sample was also influenced by convenience. The researcher travelled to many different districts to conduct interviews and some potential participants were unavailable at the time the researcher was in their area.

Participants were aged between 12 and 18 at the time of the interview. The youngest participant was in Year 8 at school, and the two oldest were attending university. All other participants attended high-school. Participants were seven females, and three males. They were aged between 2 and 17 (Mdn = 7 years 10 months) when their sibling was diagnosed. Their sibling’s treatment had finished between 10 years and 6 months prior to the interview (M = 3 years 6 months). Participants lived in various locations across the country, therefore some had their sibling’s primary treatment at their local hospital, others moved towns to be closer to hospital, and others lived long distances from the main treatment centre so family members had to fly or drive long distances to visit each other. Nine participants were Pakeha; the final participant’s ethnicity is not given in order to protect this participant’s privacy.
Interviews

Most interviews were held in participants’ homes, and one was held in a private room at a university which was easily accessible to the participant. After being presented with a participant information sheet (Appendix F) and discussing the interview with the researcher, participants over the age of 16 gave written consent to complete the interview and for this interview to be recorded and described by an independent transcriber. For participants under the age of 16 this process was completed with parents and siblings present and parents gave written consent for their child, who also gave written assent to participate (consent and assent forms are in Appendix G). Prior to the meeting, participants and parents were informed that a quiet room without interruption was required for 40-70 minutes for the interviews. Despite this, three interviews were briefly interrupted by family and visitors. However, all rooms were private for the vast majority of the interviews with at least one closed door, or a long corridor between participants and the rest of the family.

Interviews followed a semi-structured schedule so specific questions and topics covered varied according to each participant.

At the start of the interview, participants were asked to introduce the interviewer to their family and context, providing a brief description of family members and relative ages. Following this, participants were invited to talk the researcher through a loosely chronological description of their memory of what had happened during their sibling’s treatment. This provided a context for the researcher to interpret later comments. During this process they were prompted with “how was that for you?” to re-orient them to speaking about their experiences as a sibling if they focused heavily on their sibling’s or parents’ experiences. They were also asked about the frequency of thoughts about cancer, and any involvement with organisations through cancer.

The body of the interview contained two main sections: Firstly, participants were asked about things that were helpful in dealing with their sibling’s cancer and things that made it harder to deal with their sibling’s cancer. And secondly, they were asked for any advice they would like to give to organisation, parents, child-cancer patients, or other siblings about the experience of being a sibling of someone with cancer.

In the conclusion of the interview, participants were asked to reflect on how they thought their experiences with their sibling’s cancer had influenced or changed them. The interview was closed by asking if there was anything else they wanted to add or anything they had expected to
be covered in the interview that had not been mentioned. The final question asked participants to comment on the interview process, particularly how familiar they were with talking about cancer from their perspective.

Following the interview, participants were informed that if they thought of anything else they would like to add, or if there were any comments they wanted removed from the transcript then they could make contact within 14 days to have the transcription adapted or deleted completely. No participants used this opportunity. After two weeks, a professional transcriber was sent recordings of interviews. The resultant transcriptions were re-checked twice by the primary researcher for accuracy, and as part of the process of familiarisation with the data.

**Thematic analysis**

Thematic analysis is a qualitative research method for “identifying, analysing, and reporting patterns (themes) within data” (Braun & Clarke, 2006, pp. 79), resulting in the identification of a number of themes and subthemes which describe the data in detail. Thematic analysis has a number of advantages in comparison to other qualitative data analysis techniques which make it a suitable choice for this study. Firstly, the results of thematic analysis are accessible to the general public and other stakeholders (Braun & Clarke, 2006). For this research, the charities involved in recruitment, along with families who participated have indicated an interest in obtaining the results, so it is important that these results will be interpretable outside academia. Secondly, thematic analysis allows summaries to be made from a large and varied body of data (Braun & Clarke, 2006). This project covers a broad range of experiences within the population of siblings of cancer survivors and seeks to provide a rich description of their report of their experiences. Thirdly, thematic analysis tolerates diverse views and experiences by allowing for the simultaneous identification of similarities and differences between participants (Braun & Clarke, 2006). The experiences of siblings of cancer survivors vary widely although there are shared experiences. Finally, thematic analysis has a clearly demarcated method outlined by Braun and Clark, making it accessible to a beginner researcher such as myself. As a disadvantage, thematic analysis may be limited in its applicability and interpretability when it is conducted outside a pre-existing theoretical framework. The steps taken to conduct thematic analysis in this project correspond to those outlined by Braun and Clarke (2006) and are described below:
**Becoming familiar with the data.**

The first step of thematic analysis is to become familiar with that data. As the interviewer and primary researcher, I had first-hand experience of each interview. Furthermore, audio recordings of interviews were listened to twice to check transcriptions for accuracy. Finally, transcripts were read through a number of times making notes and recording ideas for initial codes.

**Generating initial codes.**

The second phase involves generating initial codes. This was completed manually with transcripts read systematically and excerpts grouped into one or more codes. Potential codes were identified inductively rather than searching for specific concepts.

**Searching for themes.**

Phase three is a process of sorting codes into potential themes. Mind maps showing relationships between codes were made, and these were grouped into potential themes according to codes that were conceptually related.

**Reviewing themes.**

In this step, the potential themes proposed in the previous phase were reviewed through checking the excerpts contained in each theme to see if they created a coherent theme. Following this, the original transcripts were consulted again, to see if the themes identified represented the original dataset accurately without significant gaps. This was repeated with adaptations to themes and subthemes made each time until a set of themes was identified that represented the data set well.

**Defining and naming themes.**

This step is a process of further refining themes by sorting excerpts within themes into subthemes and identifying the aspects of the theme that are identified by different excerpts. Themes and subthemes were organised in a logical order to create a narrative, and themes and subthemes were named.
**Producing the report.**

The final step of thematic analysis is writing the report. This requires themes to be described briefly, and the selection of demonstrative excerpts which capture the essence of particular themes and subthemes (Braun & Clarke, 2006).

The results of the thematic analysis are presented below.

**Personal disclosure statement.**

Qualitative research is a very personal process. Given the same subject matter and research aims, two researchers are likely to design two different interview schedules. Furthermore, the process of the interviews will vary according to the interviewer’s personality and deliberate and accidental attention to different details. Finally, the identification of themes and subthemes may also vary depending on the researchers biases. For that reason, it is important for qualitative researchers to be explicit about any biases, and how these may impact on their process of conducting qualitative research. In terms of my own biases, I am not a sibling of someone with cancer, nor have I had cancer. I did not know or know of any children with cancer, or any siblings of children with cancer until my late teens. My interest in this topic came through volunteering with Camp Quality, as a ‘companion’ on summer camps for children with cancer. Occasionally siblings attended camp but often they could not come due to limitations on places which were prioritised for the patients/survivors. I volunteered with Camp Quality on six camps before conducting the interviews, and always advocated for siblings to be more involved in camps. In terms of my own experiences as a sibling, I have an older brother and an older sister. Nine years ago my sister told the family she intended to join the Catholic Church as a habited religious sister. Although this changed the dynamics in the family a little, the more obvious difference was in the reaction of the community, particularly in my small home town and among church members from the church I grew up. I have had the uncomfortable experience of being asked “how is your sister?” often by people who I do not know, and who do not know my name. I have also heard myself referred to as “the other Riddick girl” and occasionally have met people and had them exclaim “oh your sister’s the nun?! I’ve heard of her”. Due to these experiences I may have been more likely to identify with and focus on similar experiences the participants have had. In saying this, examining siblings’ relationships with people outside the family was
also an explicit goal of the study given the impact peer relationships have on adolescent adjustment in the general population.

**Interview study results**

Six themes were identified inductively through the process of thematic analysis. These have been named ‘stress and distress’, ‘I wasn’t anyone’s priority’, ‘coping’, ‘feeling involved’, ‘it’s not all negative’, and ‘connection and disconnection’. Each of these themes contains between three and five subthemes. The themes and subthemes deal with the experience of cancer, and impact of cancer on siblings of cancer survivors, as described by adolescent sibling participants. The themes cover participants’ reports of things that made it easier and more difficult for them to deal with their sibling’s cancer. They also describe both positive and negative long-term effects of their sibling’s cancer. Each theme and corresponding subthemes are discussed below. Participants have been randomly labelled P1 to P10.

**Figure 1. Themes and subthemes**

<table>
<thead>
<tr>
<th>Themes</th>
<th>Subthemes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stress and distress</td>
<td>• Cancer is hard</td>
</tr>
<tr>
<td></td>
<td>• It wasn’t just cancer</td>
</tr>
<tr>
<td></td>
<td>• Lasting effects</td>
</tr>
<tr>
<td>I wasn’t anyone’s priority</td>
<td>• There was no-one there for me</td>
</tr>
<tr>
<td></td>
<td>• Everything revolved around them</td>
</tr>
<tr>
<td></td>
<td>• Special treatment</td>
</tr>
<tr>
<td>Coping</td>
<td>• Silent endurance</td>
</tr>
<tr>
<td></td>
<td>• Just get on with it</td>
</tr>
<tr>
<td></td>
<td>• Thinking positively</td>
</tr>
<tr>
<td></td>
<td>• Gaining support</td>
</tr>
<tr>
<td></td>
<td>• Idiosyncratic coping</td>
</tr>
<tr>
<td>Feeling involved</td>
<td>• Feeling left out</td>
</tr>
<tr>
<td></td>
<td>• Being informed</td>
</tr>
<tr>
<td></td>
<td>• Helping out</td>
</tr>
<tr>
<td>It’s not all negative</td>
<td>• It’s just normal</td>
</tr>
<tr>
<td></td>
<td>• Fun!</td>
</tr>
<tr>
<td></td>
<td>• I’ve grown</td>
</tr>
<tr>
<td></td>
<td>• Our family is closer</td>
</tr>
<tr>
<td>Connection and disconnection</td>
<td>• Lack of understanding</td>
</tr>
<tr>
<td></td>
<td>• People responding badly</td>
</tr>
<tr>
<td></td>
<td>• Bonding with fellow survivors</td>
</tr>
</tbody>
</table>
Stress and distress

The first theme ‘stress and distress’ describes the difficult aspects of being a sibling of a child with cancer. Three subthemes describe varying aspects of the difficulties faced by participants. The first subtheme ‘cancer is hard’ reports participants’ descriptions of some of the most difficult parts of cancer treatment for siblings of patients. The second subtheme ‘it wasn’t just cancer’ describes concurrent stressors faced by many participants which added to the stress and difficulty faced in their lives. Finally, the subtheme ‘lasting effects’ describes some of the negative longer-term impacts of cancer on participants.

Cancer is hard.

As described in the literature review, cancer is a severe disease, typically involving very intensive treatment and often involving severe subsequent illnesses such as life-threatening infections. In interviews, participants described some of the most difficult things about cancer treatment for siblings. Participants described distress resulting from seeing or hearing their sibling in pain, unhappy, being forcibly held down by multiple people to receive treatments, or seeing them visibly impaired because of treatments, cancer or related illnesses. Participants also described frustration with restrictions placed on them for infection control, such as wearing gowns, not inviting friends over, not visiting hospital, and standing far away from their sibling when they visit. Participants reported struggling with the unpredictability of cancer and consequent illnesses such as infections, and missing their sibling and parents when they did not get to see them often. Finally, many participants were aware that their sibling could die, or be permanently impaired by cancer and resulting treatments and illnesses, and this caused anxiety and low mood. The events faced caused participants to feel overwhelmed and stressed, resulting in emotional lability and outbursts of tears and anger. Participant P1 describes the strain of seeing his/her sibling in hospital:

“I’d kind of pretend I was fine with it and then when I was away from it get more upset I guess. Like no kind of specific reaction but I guess the more and more it happened the longer it went on for the kind of more down I started to feel. (P1)
**It wasn’t just cancer.**

Participants reported a number of stressors that overlapped with their sibling’s treatment or occurred in the time since then which have contributed to their stress. These stressors were often independent from cancer, but many were also peripherally related to their sibling’s illness, and how it was dealt with by other family members. Some of the more significant stressors faced included parental separation, death of extended family members, major surgery in the participant or other immediate family members, and moving city/house/school. More continuous stressors included school or exam pressure, peer-bullying, fighting and violence within the family due to stress, birth of new siblings, and financial strain.

**Lasting effects.**

This subtheme focuses on participants’ reports of the negative impact cancer has had on them (positive impacts from cancer are covered in the theme ‘it’s not all negative’). In terms of negative outcomes, participants mentioned on-going anxiety, both about their own health and their sibling’s health. Regarding their own mental health, two mentioned receiving treatment for depression and anxiety disorders, the onset of which they attributed at least partially to the stress of their sibling’s illness. Another described trauma-like symptoms of flashbacks and nightmares related to her sister. Still more reported personality and mood changes, specifically being less happy, more vulnerable and sensitive, having lower self-esteem, and impaired social understanding:

*I think if my parents weren’t divorced and if my sister didn’t have cancer I would be a very, very different person and I would be smiley, happy you know, I would know what kind of friends to make.* (P3)

Others commented on the impact cancer had on their world view:

*I think possibly a combination of like divorced parents and [sibling]’s illness kind of triggered that sort of sense that you can’t expect things to remain the same or you can’t necessarily rely on things to always work out.* (P1)
I wasn’t anyone’s priority

The second theme that was identified relates to the participants’ feelings of being forgotten and of being of secondary importance to their sibling who had cancer. The first subtheme relates to feelings of being unsupported during a difficult time, and a sense that their needs had been forgotten. The second subtheme focuses on participants’ frustration with the attention liberally given to their brother or sister, whose wellbeing seems to become of primary importance to everyone. The final subtheme focuses on special treats and attention their ill brother or sister received, and the jealousy and associated emotions that accompany special treatment. It is important to note that some participants found it difficult to discuss aspects of this theme as they felt their descriptions were insensitive to their siblings’ and parents’ difficult situation.

There was no-one there for me.

Participants recalled a feeling that they were alone, and/or unsupported during their brother or sister’s treatment for cancer. This feeling of being alone related to contacts both within the immediate and extended family, and their wider networks. The thoughts and feelings of being “forgotten” (P6), “shoved somewhere” (P3) and “neglected” (P10) were difficult for siblings, and when asked about advice they would give parents in terms of dealing with siblings, a lot of advice revolved around this topic.

Although they longed for their parents’ attention and support, participants were cognisant of the fact that their parents were extremely stressed, and were conscious of burdening them further with their own problems. Furthermore, they did not want to appear selfish, and were aware that their own problems were minor in comparison with their unwell sibling’s. In consideration for their parents’ predicament “how do you prioritise three other kids with one sick kid?” (P7) many participants expressed a desire for a companion of some kind. Depending on the participant, this companion could distract them from what their sibling was going through, talk (or listen) to them about how their sibling’s illness affected them, or explain some of what was happening. As one participant said:

I think what I would have needed when I was going through that time was just someone for me to talk to and just someone to be my friend and to hang out with and to make me smile.

(P3)
Some participants suggested it would be good if professionals anticipated their needs by making it an expectation that patient’s siblings would require support and companionship, this would reduce the guilt associated with asking for help.

The difficulties they experienced with feeling alone and attempting to gain support are illustrated in this excerpt from the interview with P1:

Interviewer: Is there any advice that you wish you could tell to parents about what they should do with their siblings, their children who aren’t sick?

Participant: Don’t forget the other one. Support the sick kid, but always kind of make sure that the feelings of the other kid are taken into account, and I’m not saying this as if my parents didn’t take my feelings into account.

Interviewer: But it was important that it happened?

Participant: Yeah, and I never felt quite like I could talk about how it was hard for me just because I knew it was harder for [sibling], like she was the one going through the pain and so I couldn’t you know, tell my parents that I find it hard going through this. (P1)

Some participants tried turning to their peers for support. However, this was often more difficult than they had expected. Partly because as P8 explains:

Like they don’t quite understand and they don’t really want to understand or if they do, they don’t know how to ask in what kind of way to understand it. (P8)

Everything revolved around them.

Alongside the sudden loss of attention described above, participants noted a substantial increase in attention and interest directed towards their brother or sister. As above, the current subtheme applies in contexts both within the family, the hospital environment, the wider community, and sometimes their own peer group. Within the family, one participant reported that “we sort of all had to work around whatever she was feeling, whatever she wanted” (P1). Outside the family, participants reported frustration with fielding enquiries from many people, including people they barely knew, or who did not know their sibling, about their sibling’s
health. There were exceptions to this pattern, and participants recalled fondly those times where someone asked them “how are you?”

Participant: “I guess a couple of people, when he was going through treatment, they asked me how I was doing and stuff, not like “oh how is your brother?” and stuff. They were like “are you alright?” and I was like “oh yeah, yeah [sibling] is doing well”. And they were like “yeah but are you alright?” I’m like oh, that’s nice that they’re worrying about me for a change.

Interviewer: That does sound nice. Did that happen very often?

Participant: not really. (P2)

Two participants commented on the peculiar situation of being asked “How is your brother/sister?” rather than “How are you?”

Well I think it’s okay because they’re worried about him. But they’re not as worried about me. So they’re more worried about some guy that they have probably never met than me. (P5)

It feels like you’re sort of a messenger, like you’re not really important to them as someone they’re not even talking to. Feel quite, mmmhm. (P10)

To the siblings quoted above, being asked “how is your brother/sister?” was a frustrating experience because they interpreted these enquiries as implying that they were unimportant and that their health and wellbeing was irrelevant.

Special treatment.

As described in the introduction, cancer creates both special needs and special opportunities and treatment for the young patient. For the patients’ siblings, this can be difficult to understand and accept. Many participants spoke about feelings of jealousy towards their sibling. These disclosures were often accompanied by tearfulness or noticeable nervousness in the interview. Most of these participants also said that the feelings of jealousy were something that they had not spoken about before as they felt guilty for having jealous thoughts and ashamed of speaking about them. Jealousy was linked to a number of different experiences including gifts
and experiences given by parents and charities to the child who had cancer, decreased chores even after they are well, and extra attention to their health:

> Like if he gets a bad flu or something or a bad cold, if it was me or [other well sibling] it would just be like who cares, but if it’s [sibling who had cancer] then they’re [parents] freaking out about it and then me and [other well sibling] will just look at each other and think “if that was us they wouldn’t be like that”. (P2)

Participants also talked about how the jealousy diminished and they came to terms with the special treatment their sibling received. The most important factors for reducing jealousy were seeing their sibling, and knowing about their sibling’s condition. When participants understood the pain and difficulty their sibling faced they were more able to sympathise with their sibling, and understood why others were compelled to give them things to make them feel better. In the same vein, they reported their jealousy had diminished with their age, as their understanding of cancer increased. However, this increased understanding was also associated with increasingly painful feelings of guilt and shame for having had jealous or resentful thoughts and feelings.

**Coping**

Participants discussed ways in which they coped with their siblings’ cancer. This discussion included active strategies for dealing with their experiences, as well as passive strategies and covered the time period from their sibling’s diagnosis to the current period. Subthemes are based on different styles of coping. The first coping style is ‘silent endurance’ in which participants discussed keeping their experiences private. The second subtheme ‘just get on with it’ incorporates strategies for keeping busy and distracted from their sibling’s experience. The third coping style; ‘talking about it’ incorporates processing their experience with other people. ‘Thinking positively’ the fourth coping style incorporates strategies of remaining hopeful for the best outcome, and seeing their current situation in the most positive light. Finally there were a number of ‘idiosyncratic’ strategies which are described in a fifth subtheme.

**Silent endurance.**

Many participants spoke about enduring their experience without ever talking about it. Many participants mentioned that they were increasingly inclined to talk about their sibling’s cancer as time passed than they were at the time of illness. Participants reported avoiding the
topic, and particularly avoiding discussions of how it had impacted on them, and showing their emotions. When asked about reasons for keeping quiet, some interviewees explained their choice simply: “just not wanting to talk about it, like it was kind of like a sensitive subject really” (P4). Older participants identified their silence as a type of impression management: “I didn’t want my friends thinking that I was an emotional wreck or anything like that” (P8); and “I don’t want to sound like I’m some mental case, with a really screwed up life” (P7). However, despite their choices to remain silent, a number of participants also reported appreciation for offers of support. Although they often chose not to use this support, their friends offers of support were meaningful and left the participants feeling more in control of how much they could share if they wanted to:

They [participant’s friends] were there to talk with if I ever needed to talk. I didn’t really talk to them about the stuff. ... They did say when they first knew it was happening, they said if you ever do need to talk, if you ever need anything we are here. So it’s just up to you, you can say anything. ... I find that I talk to them about it more now than I did then. (P8)

Finally, silence was also used as protection: protecting themselves from bullies who would use it against them; and protecting others who siblings felt may become overburdened if they were required to support the participant.

*Just get on with it.*

Participants described attempts to maintain a somewhat ordinary life, despite what was happening with their sibling. To this end they avoided dwelling on or thinking about what they and their family were going through. Strategies included keeping busy, having distractions, and keeping a regular routine. To some degree, the participants could be divided by those for whom life revolved around the hospital, and those who seldom went to hospital.

Those spending a lot of time in hospital spoke about appreciating times they got to ‘escape’:

*We just had people ... take us out for a day to a swimming pool, or take us trick or treating, stuff like that, that we probably wouldn’t have got to do otherwise. (P7)*

These participants also appreciated health professionals who allowed the hospital to become relaxed and home-like.
Those who only visited hospital occasionally spoke about feeling settled by the continuation of ‘normal’ life such as attending school and hobbies. They appreciated having some environments such as school, clubs and sports teams where the focus was on something other than cancer. As P6 explains: “[club name] was kind of good because no-one talked about it there” (P6). However it was also important that these environments (school, clubs, sports) understood their situation so they did not expect as much of the interviewee during difficult stages of their brother or sister’s treatment. P5 appreciated his teachers’ relaxation around rules while his sibling was receiving treatment:

_A few of my teachers last year, like if I didn’t do my homework, they weren’t yelling and screaming at me and stuff like that._ (P5)

Some of these participants, particularly those who were young during their sibling’s treatment, also spoke in a general sense about cancer not occupying much of their attention, because it did not seem especially important in their life.

_Thinking positively._

When participants thought about their sibling’s cancer, most of them tried to think positively about the future and their sibling’s recovery. Approaches to positivity described by the participants included expecting the best, and appreciating the good things. Many participants used both of these approaches and conceptualised them as equally meaning ‘thinking positively’ or ‘optimism’.

Firstly, participants talked about how important it was to expect the best outcome. Most participants were aware their sibling could have died, or been permanently impaired by the cancer. However, they chose to keep their thoughts on the probability of a cure:

_Look on what’s going to happen. Think of the positive things, not the negative things. So the things that you want to happen, not that could happen._ (P5)

Confidence in the assumption that their sibling would be fine was drawn from a number of sources. Participants expressed confidence in medical professionals: “Most people don’t die because people, everyone knows the cures and everything” (P3) and drew confidence from knowing their sibling:
A little bit worried, but not worried, because he’s [sibling’s name] and he can go through anything, and he has and he always will. (P8)

Some siblings also said they expected the best because they did not know any better, either because they were not aware of the risks, or because the risks did not seem real: “I guess I just decided she wasn’t going to die and yeah, that was pretty much it” (P6). Accordingly, most participants were re-assured by comments such as “s/he will be alright”.

However, it is important to note that one participant presented an alternative view. This participant strongly rejected optimism in favour of “being realistic” (P7) stating:

For me it was just being realistic and knowing the truth and knowing what was happening. I was so young but still that’s how I needed to deal with it. (P7)

Alongside this, some participants acknowledged that while optimism had been a very helpful coping strategy for them, it may have been unhelpful if their sibling actually had died.

The second approach to positive thinking involved comparisons with others in a worse situation. Many of the interviewees reported feeling better about their own circumstances after meeting people from families in which a child had died from cancer, or who had more intense treatments, or who had a more stressful situation in some other way. Through meeting bereaved siblings, participants reframed their own circumstances and learned to appreciate that their sibling survived:

And looking on the upside like yeah I’ve been through shit but there’s people out there, I’m lucky to still have [sibling] here. A lot of siblings have lost their siblings, so just looking at ways like that really does help. (P7)

In terms of on-going coping, participants spoke about focusing on appreciating their sibling, and the positive outcomes that have come through their experiences. Positive outcomes will be discussed in more detail under the theme ‘it’s not all negative’.

Gaining support.

Notwithstanding the previous subthemes in which participants described their reluctance to discuss their experiences and how it had impacted on them, a number of participants also spoke about using support from others to cope with their circumstances. Participants received
emotional support from family members, friends, people with a history of similar experiences, and professionals including counsellors, doctors, and hospital and cancer-organisation employees. Most participants had only accessed this support in the time since treatment finished, and some had not accessed support at all.

In terms of professional support, two participants had used medications to deal with depression and anxiety resulting from their experiences, and four mentioned seeing counsellors with varying degrees of success. Many spoke positively of the support received through CanTeen, particularly the REAL camp for those who had attended. On participant described this camp:

_There’s a thing called REAL camp which is like a Relaxed, Energising, Let go and that’s amazing. Everyone cries and there’s this big ceremony where you hold onto rocks which are burdens in your life and you put them down and say what they are. There’s so many things like that and it’s just amazing. You just feel like such a different person at the end. That’s probably one of the best experiences in my life so far. It’s amazing._ (P10)

Other participants spoke about the close supportive relationships formed with family members as they learned to support each other. One participant strongly believed in using family as supports as they will always be available, this participant said:

_Talk to your parents. Ask questions, don’t bottle up your feelings because you can’t handle it, it will get too much at some stage and just yeah talking whether it’s your grandma or your best friend, girlfriend, just talk to someone about it and have someone there that you can trust and just cry or scream at or just because if you don’t have that it’s really hard._ (P7)

*Idiosyncratic coping.*

In addition to the above subthemes which describe common coping strategies, many participants had coping strategies that were unique to them. Two participants talked about coping with the stress by crying often, and two mentioned angry outbursts at friends and family which they explained as a release of pent up frustration. Other techniques included thinking “Thank God it’s not you” (P2), minimising the difficulty of their siblings’ treatment, and using humour
to relieve tension. Finally some talked about comfort-eating, getting very involved in sport and exercise, listening to and writing music, drawing, and writing.

**Feeling involved**

The fourth theme is about participants’ involvement in their sibling’s illness. This varied widely from sibling to sibling. Some were only peripherally involved, told very little about what was happening, and essentially excluded from helping. Others were very involved, attending almost all appointments and taking responsibility for a number of tasks to lighten the burden on their parents. Three aspects of involvement are described in the following three subthemes: Firstly, ‘feeling left out’ describes participants’ feelings regarding their involvement. Secondly ‘being informed’ discusses the degree to which participants knew what was happening in relation to their sibling’s health; finally, ‘helping out’ describes the ways participants helped their parents.

**Feeling left out.**

A number of participants reported feeling left out of the events occurring with their sibling who had cancer. This feeling occurred even when participants were quite involved. One participant who visited almost every day said:

> I would have liked to feel more a part of it maybe. Like I felt like I was going through the motions, but like I was always more in the background. I guess that’s just because mum and dad were always there and I was there like on and off and would come in and visit her but I was always a visitor. (P1)

Some participants attributed their lack of involvement to their young age at the time of their sibling’s treatment. However as they aged, some expressed a desire to become more involved. On talking to a sibling about some late-effects one participant said:

> I like it when she talks to me about it. I feel really involved and like I’m important enough for her to talk to me about it, but it must be pretty bad if she’s willing to you know? I like it because I feel involved but it’s quite depressing almost to see what it’s doing to her. (P10)
**Being informed.**

During their sibling’s treatment, participants had varying degrees of awareness about their sibling’s health and treatments. One knew “pretty much everything” (P6) while another “didn’t really know what was happening” (P2). Despite this variation, all participants who discussed being informed agreed it was important for siblings to be told what was happening. They gave many reasons for needing to be kept informed. Firstly, some participants recalled occasions in which adult’s behaviour led them to believe they had not been told the whole truth. When they noticed out-of-town visitors, overheard adults talking, and saw worried faces on adults, they took this as evidence that they had not been told the truth. Secondly, siblings need accurate information because they are often the ones that communicate with the wider community. Thirdly, in the absence of information, participants sometimes assumed the worse. One participant described the result of having information kept from her:

> You go into her room and it was like “what’s happening?” and she’s only getting x-rays but I think she’s going into operation or something and it just made it difficult and it made me angry that they weren’t telling me anything. (P3)

Of those whose were kept informed, a number of participants commented on their parents’ approach to information sharing as one of the most helpful things for them dealing with their sibling’s cancer.

> My parents made it better when I was a kid ... they just talked me through it and stuff. But they didn’t bring it on too heavily or anything. They did it lightly. Then they told me later on when I was old enough. (P9)

**Helping out.**

For many participants, their involvement with their sibling’s cancer took the form of helping out in some way. Particularly among those who were older at the time of their sibling’s treatment there was talk about having a job or role in assisting their parents and sibling(s). Other participants expressed frustration with feeling helpless when they did not have a specified role. Participants helped by taking responsibility for more household jobs, such as cleaning, cooking, and looking after younger siblings. Participants were also often responsible for communicating with people outside the hospital, co-ordinating visitors, and collecting donated resources: “like a
PR kind of guy, talked to everyone, tell everyone what was going on, from what I knew” (P8). On occasion, participants were asked to help out in hospital and they spoke positively about these times, and how this made them feel included and important:

One memory that really sticks out from that time is when mum got sick and when they were up for [sibling’s name]’s treatment, that was when the big treatments were so I had to go, well I wanted to go up and look after [sibling] while mum was sick. Yeah I remember pushing her around in the pram to go up for her treatments from the Ronald McDonald house.

Interviewer: What was that like for you? How old would you have been then?

Participant: Probably 11/12. I remember like, um, looking after [sibling’s name] and stuff and waiting around while she got her treatment and just looking after her really.

Interviewer: Do you remember what you thought or felt about it?

Participant: It was kind of fun because I got to look after [sibling’s name] and spend some time with her. (P4)

All participants with jobs found it rewarding to assist, and none expressed any resentment at the additional responsibility:

It just felt like something I had to do. I had no other way around it. I couldn’t just sit in a corner and play games all day. I had to just be what we were doing. So just didn’t feel much different. (P8)

It’s not all negative

Through the interviews, it was clear that none of the participants felt that having a brother or sister with cancer was an entirely negative experience. Within this theme, there were four main subthemes. The first subtheme reports participants’ perspectives that cancer is now a regular part of life, and that although it may seem like something difficult or unusual to other people, to them ‘it’s just normal’. The second subtheme is ‘Fun!’ which includes things which made treatment fun, and fun things to have come from their experience, as well as good memories. The third and fourth subthemes relate to positive long-term changes, one to positive
growth as an individual which resulted from the cancer, and the other to positive changes in their family, particularly growing closer to one another.

It’s just normal.

When asked how often they thought about cancer, answers ranged from “pretty much every day” (P2) to “normally just when other people mention it” (P4). However, for those who thought about cancer regularly, it was often associated with looking forward to events for survivors, or otherwise “weaved into our everyday life” (P2). The benefit to frequent reminders was:

It just kind of makes it feel more like when you hear the word ‘cancer’ it’s not like, you know immediately everything comes back and you just feel sad or whatever, it’s just regular. (P2)

Although most recognised cancer had caused a change in their families, they struggled to identify what this change was, because it was all they had ever known:

We are just as normal as anyone else. We still do the same things. It’s changed us but it doesn’t seem different because it’s just what happened. (P8)

Fun!

Participants had had fun through and because of their sibling’s cancer. The fun ranged from humour and celebrations around treatment, to opportunities provided by charities supporting their families, and support provided by their communities and the hospitals. Furthermore, participants had fun playing with their brother and sister, and talked about how much they valued spending time together. Many participants spoke positively about the experiences provided by charitable organisations, one commented:

It’s given us some good times, we’ve had something to remember or if [sibling] didn’t have cancer then we wouldn’t be able to do this, and I bet you families around the world aren’t doing this right now. So it kind of, it gives us good memories to look back on and smile at I guess. (P3)
I've grown.

All participants reported that they had changed as a direct result of their sibling’s cancer. Furthermore, all participants reported that this change was mostly positive. The main theme of positive growth was increased maturity: having an improved perspective on life, knowing more about what was possible, and being emotionally stronger, more responsible, and independent. However, alongside this, many also acknowledged a downside to increased maturity. Some reported having difficulty tolerating the frivolity of their age peers, and others worried their peers may see them as boring or arrogant.

I’ve had to grow up so much more independently, like I’m so much, mature. So independent and grown up about everything. Like all my friends, I envy people my age who can just muck around and go out and be stupid whereas I think “no that’s, why would you do that?” it’s like I’ve already grown up I’ve sort of lost my childhood. (P10)

Additionally, many talked about an improved ability to see the bright-side of a difficult situation, and a desire to make the most of life and relationships. They also reported they were more likely to be compassionate to others going through a difficult situation, and would forgive and build deep relationships where important. Finally some participants also disclosed a desire to help other people in a similar situation, by raising and donating money towards charities whose support they had valued, and by volunteering for charities when they were old enough.

Our family is closer.

The contents of this subtheme did not apply to all participants; however the majority reported that their family had grown closer together through their sibling’s cancer. This trend applied even when parents were separated. Participants spoke about a change in their sibling relationship:

We talk a lot more and we’re more sort of like even sort of, we take each other quite a lot more seriously now maybe than we did and also I guess like from me I just appreciate the fact that you don’t take your siblings for granted. I mean, you don’t think of your siblings dying but when you’re put in that position. (P1)
Also, as a whole family participants reported they could speak more easily to parents and grandparents, and enjoyed time spent in family activities.

*We’ve come closer as a family and me and [sibling] personally, yeah we’ve come closer and more together. Same with the rest of the family, came closer. (P9)*

In contrast to this general trend, some participants acknowledged divisions in family alliances based on who had spent time with who during their sibling’s treatment.

**Connection and disconnection**

The final theme discusses issues of joining with people through shared experiences, as well as separating from people due to non-shared experiences. The theme focuses on relationships with people outside the family. The first subtheme describes the difficulties participants reported outsiders had in understanding the effect cancer can have on a sibling. The second subtheme describes inappropriate or inadequate responses people had to the participants as siblings of children with cancer. The third subtheme is in contrast with the previous two and presents the camaraderie experienced when participants met other people who have had similar experiences to them.

**Lack of understanding.**

A number of participants commented on how poorly understood ‘sibling-cancer’ is. In addition to asserting that they had experienced a hardship through their sibling’s illness, participants talked about how strange it was that this was not recognised or understood by many people:

*I found it kind of hard, and I found it hard that people thought because I wasn’t there I wasn’t experiencing it so much. (P1)*

*It affects a lot more than people think, and it’ll be there for the rest of my life. It’s a lot harder than people think. (P7)*

This lack of understanding was linked to the over-emphasis on the patient’s wellbeing, as described in the subtheme ‘everything revolved around them’. In the interview, all participants were asked about their experience with talking about their experience of their sibling’s cancer,
and while many said they had discussed it before, a number also said they had never been asked about what it was like for them:

Interviewer: Have you talked about it much, like in terms of what it was like for you as opposed to what it was like for [sibling]?

Participant: Nah, no-one really wanted to listen so I didn’t really care. I just didn’t tell them. (P6)

People responding badly.

Many participants reported that it seemed as though people were intimidated by their sibling’s cancer and therefore did not know how to respond appropriately to the siblings of the patient. In its more minor forms, this led to siblings keeping quiet about their experience:

Generally people don’t know what to say. They don’t know how to approach it. They don’t know whether if they say something it would offend you or not so they kind of just let it be. (P8)

At a more moderate form, it led to social isolation, as people did not know how to act around siblings, or how to be supportive. Participants reported their peers withdrew from them socially:

Participant: I just felt sort of left out I guess. My friends didn’t know how to treat me and stuff.

Interviewer: Is there anything you would have liked your friends to have known about how to treat you?

Participant: I just want them to treat me the same but they just didn’t do that.

Interviewer: What changed?

Participant: They stopped inviting me over and stuff (P6)
Finally, for a number of participants, this intimidation led to bullying or teasing from their peers about their sibling’s illness. Participants reported feeling very upset by nasty comments made about their siblings.

*Interviewer:* When you talk about the bullying and that, was that in relation to [sibling]’s cancer or was it completely separate?

*Participant:* Yeah it was, it was like “oh your sister had cancer, shame on you, it’s your fault” and so it did put a lot of pressure on me. (P3)

**Bonding with fellow survivors.**

In contrast to the difficulties siblings had joining with other people, a number of participants spoke positively about the relationships they had built with fellow ‘survivors’. In addition to those met through camps and events specifically targeted at their population, a number also talked about school friends they had made who had some sort of significant hardship in their life, such as a serious illness of their own, or a parent who was very ill or had died. These relationships were characterised by a deep understanding, despite what was sometimes a relatively short acquaintance:

*It’s just because they understand where you are coming from. You can hear other people’s stories and stuff. You can’t, like nobody, will kind of look at you sideways if you say something because they understand what you’re talking about.* (P2)

Explanations for the bonds formed with these people usually centred on having something in common with each other, and being able to share genuine empathy which came from having experienced the same feelings. Not all participants had had this positive experience and some spoke about a longing for an age peer with a similar history with whom they could discuss stories and share advice and support.
Summary of the interview study

Thematic analysis of 10 interviews conducted with 12-18 year old siblings of cancer survivors, identified six themes. The themes included descriptions of the difficult circumstances that these participants faced in their lives, and described how they coped with these events, and the long-term impact they perceived their brother or sister’s cancer as having on them.

The first theme ‘stress and distress’ described the most difficult aspects of their experience, including things both in their situation and in their sibling’s cancer which made it more difficult for them to cope, and the long-term effect of cancer on their adjustment. The second theme ‘I wasn’t anyone’s priority’ described instances of jealousy or perceived favouritism and special treatment. This theme also outlines how participants dealt with these feelings. The third theme ‘coping’ describes coping techniques named by siblings for dealing with the stress of having a brother or sister undergo treatment. The fourth theme ‘feeling involved’ talks about siblings feelings of connection and their role in their family after their sibling’s diagnosis. The fifth theme ‘It’s not all negative’ emphasises participants’ reports that cancer was not a completely negative experience. This theme included positive experiences and outcomes to come from the cancer. Finally, the sixth theme ‘connection and disconnection’ describes interactions with people outside their family, including disconnection from peers and community members, and connection with other people who have had comparable experiences.
Chapter Five: Discussion

Chapter summary.

This chapter discusses the results of the questionnaire study and the interview study exploring how they relate to one another, and how they relate to previous research. The previous three chapters have outlined the methods and results for a questionnaire study and an interview study completed with 12-18 year old siblings of cancer survivors in New Zealand. This chapter aims to interpret the results of these studies in the context of the existing literature, and to outline implications of the results, alongside strengths and limitations of the research. Finally, implications of this study will be summarised and recommendations made for future research.

The aims for this project were to explore the perspectives of siblings of cancer survivors, taking some of the context of their lives and relationships into account to understand their psychosocial adjustment and adaptation. From this platform, we hope to recognise some of the contributing factors to poor adjustment for siblings, and some of the protective factors which support positive adjustment and prevent or reduce negative psychological adjustment.

The results from the questionnaire study showed depression rates were very high in this sample, but self-esteem was in the normal range and wellbeing appeared to be within the normal range although comparative data was not available. Being from a smaller family (less than two children), was associated with having less depression (Table 4) and higher wellbeing (Table 3). Age, gender, time since diagnosis, time since treatment ended, and length of time on treatment were all unrelated to any measure of psychological adjustment (see Table 3). All measures of psychological adjustment were highly correlated with optimism (see Table 3). Both before and after controlling for optimism, depression was significantly predicted by aspects of parental differential treatment (Tables 9 and 13), and peer alienation (Tables 5, 6, 10, and 11). Sibling warmth significantly predicted wellbeing (Tables 7 and 12) and was a significant predictor of self-esteem although it did not improve the model enough to reach significance (Table 8). This chapter will consider each of these findings in turn, integrating them with previous research and the themes observed in the interview.
Psychological adjustment

Recent quantitative research (since 1999) has mostly found that siblings of child cancer survivors as a group are not poorly adjusted; particularly in relation to negative markers of psychological adjustment such as depression and behaviour problems (Alderfer et al., 2009). However, in the present sample, 76% of participants had depression scores above the cut-off recommended by the authors of the CES-DC (cut-off = 15); the group mean (M = .96, equivalent to a total score of 19.2) SD = .58) was also above the cut-off (see Table 2). Some previous studies using this tool have also found higher than expected proportions of the sample above the cut-off (e.g. 48% of a 1,207 students in grades 4-12 in the United States) (Doerfler et al., 1988). In another study, the cut-off score was not used, but the means of a general population sample (156 adolescents aged 11-18) were above the cut-off of 15 (M_{Boys} = 18.82, SD = 11.55; M_{Girls} = 16.63, SD = 10.47) (Brage & Meredith, 1994). These findings suggest the test-author’s cut-off point may be too low to accurately exclude young people without problematic low mood. However, even considering an overly inclusive cut-off score, the proportion of participants above the cut-off score, and the mean score for our sample were higher than those given in the two studies presented above (Brage & Meredith, 1994; Doerfler et al., 1988). The presence of problematic mood in this sample is supported by the interview study, in which two out of ten siblings reported being prescribed medications to control mood problems, and an additional two participants reported requiring counselling to deal with mood and anxiety problems in the time since their brother or sister had finished treatment. The theme ‘stress and distress’ discusses the reports of difficulty dealing with their sibling’s cancer, and other concurrent stressors. In particular, the subtheme ‘lasting effects’ details the negative impact their sibling’s cancer has continued to have in their life. Previous research, which has focused on the first few years following diagnosis has failed to capture the long-term impact that cancer has on siblings. This study highlights the importance of studying and addressing the needs of siblings long after their sibling’s treatment has ended. In the subtheme ‘it’s just normal’ siblings talked about thinking about cancer daily or weekly, even though their sibling was diagnosed and had completed treatment a number of years previously.

Seen in the context of previous international research with siblings of children with cancer (see Alderfer et al., 2009), the results from this study are unusual in that they display an unusually high level of negative adjustment, and this does not vary with time since diagnosis,
age, or gender (see Table 3). Although this study is unusual in context of all international research, it more closely matches findings from other studies within Australasia. Only two other studies are known to have measured the psychological adjustment of siblings in Australasia. In New Zealand Dobson’s study with 8-15 year old (N = 37) siblings of children diagnosed with cancer between two and 17 months ago also used the CES-DC. Over half (62.2%) of their sample fell above the depression cut-off (Dobson, 2007). In Australia, Sidhu et al. (2006) assessed a sample of 31 siblings, aged 8-13, prior to a camp-based intervention for siblings of children on treatment for cancer. A high proportion (40%) of the sample fell in the ‘at risk’ (13.3%) and ‘clinical’ (26.7%) categories of the measure prior to the camp. Immediately following the camp none of the participants remained in the clinical range, although by a 2-month follow-up one participant had returned to the clinical range (Sidhu et al., 2006). The distribution of scores in follow-up administrations suggests that the original high scores were not the fault of an overly sensitive instrument. Note however that Sidhu et al. (2006) used a non-specific scale (the Self Report of Personality from the Behaviour Assessment for Children) that assessed emotional disturbance, particularly internalising disorders (such as depression, anxiety, somatisation). A score in the clinical range of their scale falls two standard deviations from the mean “and denotes a high level of maladaptive behaviour” (Sidhu et al., 2006, pp. 583). Another shared similarity between this Australian study and the present study is that despite high levels of negative adjustment, self-perception (a closely related construct to self-esteem) was in the normal range, which would normally indicate non-problematic adjustment (Sidhu et al., 2006). It appears that although positive and negative adjustment are linked, mood problems can develop without a loss of self-esteem among siblings of children either on treatment, or who have successfully completed treatment for cancer. This reinforces the importance of investigating multiple aspects of psychological adjustment.

Two further studies taking place in Australia did not report overall adjustment of siblings but did ask about the needs and problems of siblings, one from the sibling’s perspective, and the other from the parent’s perspective. When asked directly, siblings aged 12-24, (N = 72) identified ‘expressing and coping with feelings’ and ‘access to support services and professional help’ as two domains of need that were important for siblings (P. Patterson, Millar, & Visser, 2011). The other interviewed nine parents of children enrolled to partake in the camp intervention above at the same time as pre-camp measures were completed. One of the three
resulting themes was ‘behaviour challenges and adaptation’. Taken together, these five studies (including the present thesis) appear to present a picture of the negative adjustment of siblings of children with cancer in New Zealand and possibly Australia that is different to that found when recent international research is analysed.

New Zealand and Australia are both relatively sparsely populated countries, with a government supported health-care system. In comparison to other more densely populated countries, a higher proportion of siblings may be required to re-locate or be geographically separated from the patient during active treatment. In the interview study of this project, siblings talked about the importance of feeling involved in their sibling’s experience. Being distant from the treatment centre can isolate siblings from their brother or sister, the parent staying with the patient and the psychosocial support-services for families with cancer. When reviewing the available literature on siblings of children with cancer there did not appear to be any studies which included distance between hospital and home as a variable. In the top-ten needs (from a pool of 80) identified as important by siblings in Australia, the first, second and third most often reported ‘unmet needs’ were: 1) coping with the feeling that the sibling may die, 2) access to professional support to cope with family stress, and 3) to talk to their sibling about their feelings (P. Patterson et al., 2011). Meeting these needs is likely to be more difficult to address when distant from the treatment centre, where they cannot see their sibling regularly and are distant from professionals who specialise in the experiences of families with cancer. Participants aged 12-17 (N = 42) who reported more unmet needs also had higher scores on a measure of behavioural and emotional problems (P. Patterson et al., 2011).

Further research is required to determine if there is indeed a difference between New Zealand (and possibly Australian) siblings and international siblings, the magnitude of this difference, what causes or mediates this difference, and how to improve outcomes for New Zealand siblings. The studies in New Zealand and Australia have all had small sample sizes (below 50) and samples have not been randomly selected. Consequently, caution must be taken in interpretation. It is possible these results are an artefact of self-selected samples, or of different response styles from different populations. In particular, the New Zealand results require caution as the CES-DC, (used in both New Zealand studies) does not have norms for New Zealand children and adolescents.
Family size

The correlations (Table 3) and regressions reported on in Chapter 3 showed that depression, self-esteem, and wellbeing were unrelated to any of the demographic variables collected except family size (Table 4). Having a larger family (more than two siblings) was associated with higher wellbeing in correlations, and lower depression in correlations and a regression when compared against having a smaller family (only two siblings). The squared semi-partial correlation co-efficient from the regression predicting depression from demographic factors (Table 4) suggests that family size uniquely accounted for 18.6% of the variance in depression. This finding appears to be in opposition to research by Labay and Walco (2004) in which family size was significantly correlated with psychological adjustment in siblings of children with cancer. They do not state the direction or size of this correlation, nor how family size was measured, or which aspect(s) of psychological adjustment it was related to (parent reported internalising, externalising and social competence were the outcomes measured) but explain the findings in the discussion as follows:

*It stands to reason that as the number of individuals in a family increases, the complexity of relationships expands geometrically and the potential for struggle in meeting individual’s needs intensifies. In addition there may be increased competition for limited material and emotional resources, which only further complicates the coping needs of all involved (Labay & Walco, 2004, pp. 312).*

This explanation suggests sibling psychological adjustment was most optimal for siblings from smaller families. Similarly, the previous New Zealand study found that when family size was grouped categorically, the group of participants with four siblings had significantly higher depression scores that those with two or three siblings (only one sibling was from a family of two-children) (Dobson, 2007). In contrast, an older study from the United States found a significant positive correlation between family size and a ‘good’ adjustment summary score, but not between family size and the corresponding ‘bad’ adjustment score (Madan-Swain, Sexson, Brown, & Ragab, 1993). This finding indicated positive adjustment increased with family size. Their sample consisted of 32 siblings aged 5-16 of children diagnosed with cancer for whom ‘prognosis was favourable’. However, number of siblings is reported only for 24 siblings, 14 of
which were from two-child families, eight from three-child families, and two from five-child families (Madan-Swain et al., 1993).

One possible explanation to understand these differences in findings relating to family size is differences in how family size was measured, particularly where family size was measured categorically in two categories. It is possible that a U-shaped function would best represent the relationship between family size and psychological adjustment. Two-child families may be stressful for the sibling because they are the only well-child, making comparisons between themselves and the patient more likely, and also making differential treatment more provoking. Similarly, very large families may be stressful for the reasons given above by Labay and Walco (2004). To check this hypothesis, the siblings in the present study were re-grouped into four groups: those with one sibling ($n = 12$), two siblings ($n = 10$), three siblings ($n = 6$), and four or more siblings ($n = 3$). Graphs of mean depression and wellbeing scores (Figure 2 and Figure 3) for siblings in each group give initial support for the hypothesis that there is a U-shaped function regarding family size with optimal psychological adjustment in families with three or four children. This pattern is particularly pronounced for depression.

![Figure 2. Line graph displaying U-shaped function of depression according to the number of siblings in the family.](image-url)
In conclusion, siblings in two-child families, and siblings from large families with five or more children may be at increased risk for poorer psychological adjustment, particularly depression. This finding requires more rigorous statistical testing with larger samples to verify if it holds across samples. Research regarding siblings of children with disabilities and other illnesses may also benefit from investigating the possibility of a U-shaped relationship between family size and sibling psychological adjustment.

Optimism

Optimism was highly negatively correlated with depression, and highly positively correlated with wellbeing and self-esteem. The influence of optimism on the outcome variables was further demonstrated in the third set of regressions in which optimism was included as a fixed variable in all regressions. In all but one of these regressions optimism had more influence than any other variable on psychological adjustment (Tables 10, 12, and 13). In regressions predicting depression (Tables 10, 11, and 13), a one-standard deviation increase in optimism decreased depression by between .4 and .62 of a standard deviation, holding other predictor variables constant. This degree of change would move the group mean of depression from above...
the cut-off score into the normal range. These findings suggest optimism is an important predictor of adjustment among adolescent siblings of cancer survivors.

The correlations between optimism and outcome measures are relatively high (Optimism x Depression r (29) = -.648; Optimism x Self-esteem r (30) = .741; Optimism x Wellbeing r (30) = .770) (see Table 3). Consequently, it is worth investigating the differences between the constructs being measured to ensure that the high correlation is not entirely due to an overlap in definition of the related constructs. Previously the trait of optimism has been criticised for being analogous to self-esteem (Scheier, Carver, & Bridges, 1994). The LOT test creators, Scheier and Carver, along with Bridges defended against this criticism by acknowledging the conceptual overlap between optimism and self-esteem while highlighting the conceptual differences. They state:

_Self-esteem represents a sense of self-worth which carries the implication that one will be accepted rather than rejected by others, and that one is not a failure in one’s life. These consequences, of course, involve positive versus negative outcomes, thus linking self-esteem conceptually to optimism. As with self-mastery, what seems to differentiate this concept from optimism involves (at least in part) a kind of ascription to the self, the ascription in this case however is not one of control but rather of an intrinsic tie between feelings of worth of the self’s value and positive outcomes (Scheier et al., 1994, pp. 1064)._ 

As part of this defence, they conducted a study with undergraduate students in which they correlated optimism with both self-esteem (Rosenberg scale) and depression (Beck Depression Inventory) finding correlations of .54 (p<.001) and -.42 (p<.001) concluding that although these are related constructs, they are not entirely the same. Conceptually, depression and optimism are related in their relationship to positive or negative attributions for events, and separated by the nature of optimism as an attitude relating to expectations rather than being directly related to internal emotions or moods (Scheier et al., 1994). In relation to wellbeing, one study correlated Spanish translations of the LOT-R and Ryff wellbeing scale (Augusto-Landa, Pulido-Martos, & Lopez-Zafra, 2011) (this thesis also used the LOT and the Ryff wellbeing scale). They did not calculate an overall wellbeing score but correlations between optimism and the 6-subcales of the wellbeing measure ranged from .38 to .59 within an undergraduate student population (Augusto-Landa et al., 2011). The studies described above report smaller correlation coefficients
than those found in the current study. This suggests that optimism may be a more important predictor of psychological adjustment in siblings of cancer survivors than it is among undergraduate students.

The concept of resilience can facilitate interpretation of the role optimism plays in the adjustment of siblings of children with cancer. Resilience refers to a person’s ability to adapt in the face of adversity or trauma that might be expected to result in negative outcomes such as poor psychological adjustment (Cutuli & Masten, 2009). Having a sibling with cancer is an adversity which has been associated with negative outcomes, however not all siblings experience significant disturbance as a result of their sibling’s cancer. In terms of predicting resilience, Cutuli and Masten (2009) differentiate between two types of predictors: Firstly, ‘promotive’ factors predict positive adjustment regardless of the presence or absence of adversity, secure parental attachment is an example of a promotive factor. Secondly, ‘protective’ factors rise to special importance in the context of adversity in particular; problem-solving aptitude is an example of a protective factor because it is not necessarily an important skill until one is facing a problem. Some predictors of resilience may sit in both categories, that is, they are generally promotive of positive adjustment but become especially important when a person faces difficult circumstances (Cutuli & Masten, 2009). Optimism appears to be both promotive and protective: even in community populations it is associated with psychological adjustment, but when subjects have faced adversity, it becomes especially important in predicting positive adaptation, as shown in the correlations and regressions resulting from the questionnaire study.

In the interview study, ‘thinking positively’ was identified as an important coping strategy by most participants. Some siblings commented that being optimistic was essential to their ability to manage the stress and worry regarding their sibling’s cancer. Optimism stopped them from dwelling on negative effects of cancer, and the possibility of negative future consequences. Optimism continues to play a role in reducing anxiety associated with the risk of relapse. Furthermore, optimism, in the sense of seeing the ‘silver-lining’ of otherwise negative events also contributes to post-traumatic growth. Post-traumatic growth is growth or development occurring as a result of a traumatic experience. The positive outcomes outlined in the theme ‘It’s not all negative’ are evidence of post-traumatic growth in participants. Post-traumatic growth is associated with increased self-esteem, improved quality of life, and higher optimism (Meyerson, Grant, Carter, & Kilmer, 2011).
Parental differential treatment

The regressions conducted as part of the questionnaire study identified that parental differential treatment was related to depression, but not to self-esteem or wellbeing. In particular, in the regression model presented in Table 13, higher depression occurred with lower optimism, more parental unfairness (both significant predictors), receiving less control from parents in comparison to their sibling who had cancer, and receiving less affection from parents in comparison to their sibling who had cancer (both approached significance, p = .056 and p = .054 respectively). Caution in interpreting these findings is required, because relative parental affection was a variable identified as having low reliability (α = .56).

However, if this was a replicable and stable finding, interpretation requires acknowledgement of two findings in particular. Firstly, that parental differential treatment was associated with depression, but not with self-esteem or wellbeing. This finding held in both correlations and regression. Secondly, in the regressions, the direction of the relationships, in which the valence of the beta co-efficient indicated that receiving less control and less affection relative to the cancer survivor and perceiving this as unfair predicted an increase in depression.

The interview study findings can help the interpretation of how these items were associated with depression but not self-esteem or wellbeing. The theme ‘I wasn’t anyone’s priority’ contained reports of parental differential treatment. Participants reported conflicting emotions regarding these experiences, they felt sad, angry, and lonely because of the differential treatment, and were jealous. But they also understood some of the reasons for the differences and were often accepting of the differences; furthermore they felt shame and guilt for feeling jealous. In the interview study, siblings made it clear that although they were upset about the differential treatment, they understood why it happened. That is to say, they think it is unfair, and it made them sad, contributing to lowered mood, but it was not a reflection of their worth, so it was unrelated to self-esteem or self-concept. Previous research on parental differential treatment in community populations has found it is associated with internalising and externalising problems (Buist et al., 2013) and this is theorised to be mediated by self-esteem, in that poorly treated children might think they are treated differently because they are less deserving of good treatment (Buist et al., 2013). In the current population, when siblings notice they receive less attention than their sibling, this is attributed to their sibling’s special circumstances with cancer, as opposed to being internalised as a fault of the sibling. Furthermore, the differential treatment
being understood as unfair, and unrelated to their self-worth, this may have supported the post-traumatic growth of increasing maturity and compassion which has been reported not only in the present interview study, but in many previous qualitative studies with siblings and parents of siblings. The increase in maturity and compassion may improve their sense of autonomy, self-acceptance, and purpose in life and buffer the impact of parental differential treatment on psychological wellbeing.

Within the regression predicting depression (Table 13), depression is highest in siblings with low optimism, who perceive themselves as having less parental affection than their sibling with cancer, and less parental control compared to the sibling with cancer, and who see their parents differential treatment as unfair. With parental affection and parental control having the same valence, this suggests that it is a loss of attention that predicts depression, regardless of whether that attention is positive (affection) or negative (control). Previous studies have not always differentiated between affection and control, or the direction of the differential treatment. Instead, they have measured the degree to which parents differentiate between siblings. The more un-equally parents treat children, the more internalising and externalising problems the children display (Buist et al., 2013). The results of the present study demonstrate the value of including direction of differential treatment in analysing results.

In conclusion, parental differential treatment is an important predictor of depression in siblings of child-cancer survivors. Receiving less attention and thinking this is unfair is associated with lower mood, especially when optimism is also low. However, because of the way differential treatment is interpreted and understood in the context of their sibling’s illness, differential treatment does not significantly influence self-esteem and wellbeing.

Peer relationships

Relationships with peers were shown be important in both the questionnaire study and the interview study. In the questionnaire study peer alienation (but not peer trust or peer communication) was a significant predictor of depression in regressions both before and after controlling for optimism, improving the model from optimism alone (see Tables 5, 6, 10, and 11). No aspects of the peer relationship were associated with self-esteem or wellbeing in correlations or regressions.
In the interview study, the subject of the final theme ‘connection and disconnection’ was relationships with people outside the family. In the subthemes ‘lack of understanding’ and ‘people responding badly’ peers spoke about feeling alienated and disconnected from their peers. The previous research discussing peer relationships of siblings of children with cancer is limited. Many studies do not mention friendships or peer relationships at all (e.g. Sidhu et al., 2005; Wilkins & Woodgate, 2005; Woodgate, 2006), others have mentioned friends only as potential support groups (e.g. Chesler et al., 1992; Sloper, 2000). One exception is Alderfer and Hodges (2010) who examined 8-18 year old siblings of children with cancer 3-38 months post-diagnosis \((N = 161)\). They differentiated between ‘classmates,’ ‘friends,’ and ‘others in school’ and found a lack of support from classmates and from others in school was associated with self-reported depression (but not anxiety). Friend support was rated by siblings as the most important source of support, but was unrelated to depression or anxiety. In another study, when the needs of Australian 12-24 year old siblings were considered (P. Patterson et al., 2011), the domain of ‘Peer support (friends)’ was the domain in which the most participants reported unmet needs (Peer support from peers with similar experiences was a separate domain) (P. Patterson et al., 2011). In a third study, parents \((N = 45)\) of child-cancer survivors in the United States participated in focus groups one to nine years following their child’s completion of cancer treatment (J. M. Patterson et al., 2004). The most often reported source of community related strain was ‘parents’ friends insensitive or avoidant’ reported by 26.7% of parents, in 71.4% of focus groups (J. M. Patterson et al., 2004). The second most common was ‘child’s peers insensitive or avoidant’ reported by 23.4% of parents, in 71.4% of focus groups (J. M. Patterson et al., 2004). This suggests that difficulty with lack of understanding from the wider community is a problem for siblings, parents of children with cancer, and cancer patients.

In the interviews, participants said they had been bullied, left out of social events, and felt misunderstood when their situation was minimised or ignored because they were a sibling, rather than a cancer patient. Much of this alienation was attributed to lack of understanding of how child-cancer may impact on the patient’s siblings. This related to feelings reported in the second theme ‘I wasn’t anyone’s priority’ as people may not know to ask siblings about their experiences, thoughts and feelings in relation to the cancer. In turn, this lack of understanding may have contributed to siblings using the coping strategies described in the third theme of ‘silent endurance’ and ‘just get on with it’. In both of these techniques, siblings do not discuss
their situation with others. The items on the peer alienation scale capture aspects of openness, and willingness to share emotions with peers. For example: “I get upset a lot more than my friends know about”. Siblings who cope by avoiding discussing their feelings and experiences will likely be identified as alienated on this measure. However when these techniques are considered in the context of the negative experiences described in the final theme, the reluctance to talk about their thoughts and feelings regarding their sibling’s cancer is understandable.

Considering the findings both from this study and previous studies, it appears that community support and understanding and connection with others outside the family are important for protecting against negative adjustment. Drawing on the current study’s findings, one possible explanation is that a lack of sensitivity of the wider public may make it difficult for siblings to be open and share their experiences with friends. Siblings seem to be able to identify their need for support from friends, but report meeting with resistance when they try to have these needs met. Consequently, siblings may be more likely to cope with their stressful circumstances by avoiding discussing their experiences. However, given their growth in maturity, when reflecting, they may attribute the lack of understanding of their peers as lack of maturity. The resulting isolation or alienation may then make them feel sad and lonely, but because it is attributed to personal growth, the effect is not global, and self-esteem and wellbeing are not as affected.

**Sibling warmth**

Sibling warmth correlated significantly and negatively with both self-esteem and wellbeing suggesting participants with warmer sibling relationships had lower self-esteem and poorer wellbeing (see Table 3). This seemed to be more than a chance finding as it was evident for two out of three of the measures of psychological adjustment. Sibling warmth was also a significant negative predictor of wellbeing in regressions both before and after controlling for optimism (Tables 7 and 12). Sibling warmth was a significant negative predictor of self-esteem before controlling for optimism, although the resulting model was not significant (Table 8). None of the measured dimensions of the sibling relationship were associated with depression in correlations or regressions.

---

4 After controlling for optimism, sibling warmth approached significance as a predictor of self-esteem (p = .072), this did not represent a significant improvement to the model. Regression table available on request.
Although the current studies quantitative findings are the second study to find this direction of results (Labay & Walco, 2004) discussed below), they are contrary to theoretical expectations. Researchers have claimed that warm sibling relationships can be a protective factor for high-risk children by acting as a ‘buffer’ from adverse life events, as well as directly contributing to enhanced social and emotional development (Volling & Blandon, 2005). In the general population, sibling warmth and related concepts such as sibling engagement and sibling support have consistently been associated with better outcomes including fewer depressive symptoms (Kim et al., 2007; Milevsky, 2005), fewer internalizing and externalising problems (Buist et al., 2011), less deviant behaviour (Moser & Jacob, 2002), higher self-esteem, (Milevsky, 2005; Stocker, 1994) better behavioural conduct (Stocker, 1994), and higher life satisfaction (Milevsky, 2005) to name only some correlates. Further, a recent meta-analysis by Buist et al. (2013) assessed results from 34 studies (12,257 children and adolescents total), mostly from community samples, finding that sibling warmth was significantly related to less internalising problems (including anxiety and depression) and less externalising problems (including aggression and delinquency).

Despite the robust evidence for sibling warmth being associated with improved outcomes in most populations, there is a less clear picture in the literature regarding siblings of young people with difficulties. Increased sibling warmth has been associated with poorer outcomes for siblings of children with pervasive developmental disorders (Fisman et al., 1996), but was associated with improved or non-significant outcomes in relation to adjustment of siblings of children with down syndrome, spina bifida, and attention deficit hyperactivity disorder (Fisman et al., 1996) (Bellin, Bentley, & Sawin, 2009) (Mikami & Pfiffner, 2008). Therefore it seems that among siblings of children with special circumstances the role of sibling warmth may vary depending on the sibling’s condition.

Regarding sibling of children with cancer, the findings of the current study are in keeping with those of Labay and Walco (2004) who also found that when measured quantitatively, during their sibling’s treatment, higher sibling warmth was associated with poorer outcomes. In their case, these outcomes were social competence, externalising, and total-problem scores, all from a parent-report measure. To explain their findings of sibling warmth relating to negative adjustment in siblings of children on active treatment, they theorised that with increased intimacy, the sibling is more vulnerable to experiencing the stresses of the cancer treatment and
feeling more affected by separation and changes in their brother or sister (Labay & Walco, 2004). However, the continuation of this influence in the present study which took place after treatment cessation may indicate an alternative explanation is necessary. The trend observed could have arisen through a number of different processes. Firstly, there can be a social pressure against saying anything negative about a cancer survivor. Siblings with lower self-esteem and who experience low wellbeing may be more susceptible to this pressure and therefore report a warmer sibling relationship regardless of the reality of the relationship. This would not necessarily apply to depressed siblings, who would be more likely to see the sibling relationship as negative due to a negative attribution bias. Secondly, closer sibling relationships may be more likely to result in sibling comparisons; when comparing achievements in life, a sibling may see their personal achievements as minor in comparison to surviving cancer; reducing their self-esteem and wellbeing. Thirdly, closer siblings may be more aware of the dangers their brother or sister faced and therefore more likely to experience trauma or vicarious trauma from seeing or hearing about the difficulties of their sibling, however this would also be expected to impact on depression.

The negative association between sibling warmth and wellbeing and sibling warmth and self-esteem diverges from the current studies interview study findings in which participants conceptualised an increase in closeness in the sibling relationship as a positive outcome. However, interview participants were not asked to comment on how the sibling relationship may have contributed to their personal adjustment. These qualitative findings are similar to previous qualitative studies on siblings of children with cancer, in which increased closeness is commonly reported, and conceptualized as a positive outcome by both researchers and families (Sloper, 2000; Wilkins & Woodgate, 2005; Woodgate, 2006). Given the different appraisals of the value of a warm sibling relationship, further research is required to validate the findings from the questionnaire study and to determine the reason for these findings. However at this stage it seems that among siblings of children with cancer, high warmth within the relationship with the sibling who had cancer is not altogether positive. A focus of future research could be to examine the warmth and conflict between healthy siblings in families with three or more children where one child has had cancer. It is possible that a warm relationship between healthy siblings would serve as a buffer against negative events such as sibling cancer as it does in the wider population. This
may also explain the relationship between family-size and psychological adjustment discussed earlier.

**Strengths and Limitations**

This study is limited in a number of ways. In regards to the questionnaire study the primary limitation is the small sample size, and sample selection, and there are some limitations relating to study design. The interview study shared the same problems of sample selection with the questionnaire study.

Firstly, the low number of cases in the questionnaire study limited the number of predictors that could be entered into regressions. A larger sample size would have given us freedom to examine the relative importance of different relationships in predicting psychosocial adjustment. Furthermore, interactions between different predictors could have been explored to give a more in depth understanding of how these variables work simultaneously to influence participants. For example, simultaneously assessing the effects of parental differential treatment and the sibling relationship, as a warm sibling relationship may buffer the effects of differential parental treatment. The achieved power of the regressions conducted was somewhat low (.7), even to detect large effect sizes. This means the chance of detecting genuine relationships with small to medium effect sizes was very low. Given these limitations is it difficult to know how to interpret some of the null-findings. A null finding could occur as a result of a Type II error in which the study limitations have prevented a genuine relationship from being detected. One positive effect of this context is that the probability of a Type I error is lower so one can be reasonably confident that the relationships observed are genuinely significant.

Furthermore, the small sample size may have contributed to the somewhat low reliability observed on some measures. Consequently, results incorporating certain scales must be interpreted with caution. The significant findings which are impacted by moderately low reliability (α .45-.6) include some correlations with depression: relative maternal affection, relative paternal affection, and parental affection unfairness. Of these, only relative parental affection was used in regressions: it approached significance as a predictor of depression after controlling for optimism, parental unfairness, and relative parental control.
There were also a number of outliers, and some scales required adaptation to meet assumptions of normality (see Appendix E). Due to the low number of cases, switching to a non-parametric research method was not permissible.

Another limitation of this sample relates to how participants were recruited. This study used a self-selected sample. Participants volunteered to participate and were recruited through agencies which advocate for and provide non-medical services for families with a child with cancer. Not all families of children who have had a child diagnosed with cancer will have contact with these agencies. During the interviews, some participants still reported avoidance of reminders of cancer. This avoidance is likely to be even stronger among those who heard about the research and chose not to participate, or those who did not hear about the research due to lack of involvement with charities which may remind them of cancer. The sample also consisted mainly of siblings older than the young person who had cancer, which may have influenced results. However this seems unlikely as relative age did not have any relationship to outcome variables. Most siblings were also female, although as discussed above, gender did not have any influence on outcomes. A more representative sample may help confirm these findings.

Finally, the questionnaire design had some faults. Firstly, it did not incorporate questions about family structure, such as if siblings were full, half, or step-siblings, and if parents were together, separated, or living in blended families. Future research designs could incorporate these questions as they may support the interpretation of findings regarding family and parental environment. The questionnaire also did not ask about involvement with psychological services, or use of psychological medications. This may have influenced results as medications could have masked problems of sibling psychological adjustment. Finally, many of the measures incorporated into the questionnaire did not have normative or comparative data available for the version of the scale used. This limited our ability to interpret some of the descriptive findings.

In terms of the interview study the main limitation was due to similarities between participants. For example, while a range of ages was selected, all siblings were older than the sibling with cancer, so findings from the interview study may not be relevant to siblings who are younger than their sibling with cancer. Furthermore, although both brothers and sisters were sampled, nine out of ten sibling dyads were same-sex dyads. In previous research on sibling relationships, the gender constellation of sibling dyads has been influential in terms of characteristics of the relationship and in how differential treatment is interpreted (Buist et al.,
Furthermore, culturally, participants were primarily Pakeha, and although approximately half were asked about spiritual beliefs, all those asked denied any personal religious conviction, or a belief in a spiritual force of any kind.

Despite these limitations this research also has a number of strengths. Firstly, using more than one adjustment measure allowed a more complex understanding of how different aspects of positive and negative psychological adjustment related to different aspects of siblings of cancer survivors experiences. For example, the finding that sibling warmth was related to self-esteem and wellbeing, but not to depression, and that depression was associated with peer alienation and parental differential treatment, but neither of these predicted self-esteem or wellbeing. With only one measure of psychological adjustment the understanding of sibling experiences would have been more limited.

A second strength of this study is the range of different predictors used. Very few previous studies have assessed the influence of the sibling relationship, peer relationships, or parental differential treatment on the adjustment of siblings. Incorporating multiple relationships, with parents, siblings, and friends, prevents an overly narrow pre-determined idea of what relationships are important in an adolescent sibling’s life.

Thirdly, this study used sibling self-report for everything included in final multivariate analyses and interviewed siblings directly. In the context of the difficulty some have had in terms of bad reactions from others, and social isolation, having their voice heard is an important part of research in this population. In the interviews, siblings reported appreciating having the chance to talk about their experiences, and that someone was taking an interest in their perspective.

In relation to the qualitative study, the sample was widely distributed across New Zealand, living in urban and rural environments. Siblings from rural townships are less often represented in research due to inconvenience of travel to research centres. Siblings also represented the full range of ages involved in the study (12-18) and came from families of various sizes, with a broad range of experiences in relation to cancer and cancer treatment.

**Implications**

While the findings of this study need to be treated with caution due to sample limitations, they do highlight areas that the New Zealand organisations supporting these families could
consider helping them to understand some of the dynamics that may occur in these families. This study has identified that siblings in New Zealand may suffer more negative consequences than siblings abroad, suggesting there may be room for improvement in terms of how sibling adaptation is managed throughout the trajectory of their sibling’s cancer, and into long-term survivorship in New Zealand. However without a local reference group, it is difficult to interpret these findings. Family size may be a possible risk-factor for organisations to be aware of when assessing a sibling’s risk of developing problems with psychological adjustment. Given the U-shaped function found, it may be that children from two-child families and families with four or more children are most at risk.

Given that optimism was shown to be a strong predictor of outcomes, professionals working with these families could support siblings in developing an optimistic disposition by promoting hope, and by noticing positive growth and paying attention to positive events to promote benefit finding. Having fun also appeared to be an important part of developing a positive attitude. Having access to opportunities for fun, such as camps, family activity days, and other recreational activities may be an important part of developing optimism. Many charities already provide these services. Experiencing positive emotions in the wake of a crisis has been demonstrated to account for the relationship between pre-crisis resilience and post-crisis psychological adjustment (depression and post-traumatic growth) (Fredrickson, Tugade, Waugh, & Larkin, 2003).

Increasing parental awareness of the impact of parental differential treatment on depression may help parents reduce parental differential treatment. Parents can be supported to reduce differential treatment as much as possible, particularly after treatment has ended and the reasons for the unequal treatment are less applicable as the patient’s day-to-day health is usually no longer critical. Acknowledging that some parental differential treatment is inevitable in the wake of a diagnosis of cancer in a child, appropriate communication with the sibling throughout the developmental stages is important. Siblings in the qualitative study identified that when they understood the reasons for the differential treatment, they were better able to bear it, although it still was painful. In order for siblings to understand the changes occurring in their family, it is important that there is adequate communication between siblings and parents. Communication is not just the relay of information, but also listening to siblings’ fears and complaints, and allowing them to ask questions. Especially during the treatment phase, it seems siblings may
have few opportunities to discuss their thoughts and feelings with others. To be able to talk with a parent and have their concerns acknowledged could help siblings see that the changes are not their fault, and do not reflect on their worth.

In terms of relationships outside the family, it appears that a public lack of understanding of how cancer impacts on siblings inhibits their ability to talk to their friends, and contributes to negative experiences had with community members. This in turn makes siblings more likely to use avoidant strategies such as distracting themselves from thinking about what is happening and keeping their thoughts and feelings to themselves. These strategies are likely to result in alienation from peers, which was associated with displaying more depressive symptoms. Improving the public understanding of sibling issues may help people respond more appropriately to siblings, by acknowledging their experience, and giving them opportunities to talk about how cancer might be affecting them personally. Adults can also help siblings by providing practical support to assist siblings in continuing their usual social activities as much as possible. This would reduce the disruption to friendships caused by cancer. Furthermore, the more understanding peers have of the circumstances another child is facing the more likely they may be to respond with compassion, or less likely to bully the sibling.

Implications and recommendations to make on the basis of the sibling relationship are not clear. The finding that increased sibling warmth is associated with lower self-esteem and wellbeing is contrary to theory and the assumptions of previous qualitative researchers in this area. While further investigation in this area is needed, it may be important to identify when a sibling is over-identifying with their sibling and their sibling’s situation. Encouraging siblings to develop interests independent of their sibling, and reducing the number of comparisons made between siblings may be a first step to reducing the negative impact of high sibling warmth.

**Future research**

This project has spawned a number of questions and highlighted a number areas and topics which require further research. Firstly, further research with siblings in New Zealand is necessary to verify if findings about higher depression rates apply even when the sample is not self-selected, and when a measure with local normative information is used. Reaching potential participants through treatment providers, as opposed to through charities may also allow a larger
sample size, permitting the exploration of more variables in predicting positive and negative psychological adjustment for siblings.

This study found a U-shaped relationship predicting depression and wellbeing from family size, and also that sibling warmth did not protect against some negative outcomes, such as decreased wellbeing. Consequently, further exploration into the sibling relationships between healthy siblings in a family where one child has had cancer is indicated. In families with three or more children the relationships between well-siblings may play a role in buffering the effects of their sibling’s cancer and provide an in-built support group. Two studies have now found that increased sibling warmth between the study participant and the child cancer patient/survivors is associated with poorer sibling adjustment. The mechanism underlying this finding needs to be understood in order for this finding to translate into recommendations for families.
Chapter Six: Conclusions

Overall, this study has focused on the experiences of siblings of cancer survivors with the aim of increasing the understanding of their psychological adjustment. This research addressed a number of limitations evident in the literature base.

Firstly, this study assessed siblings of cancer survivors, as opposed to siblings of children diagnosed with cancer relatively recently. This study found that adjustment was unrelated to time since diagnosis, or time since treatment. However, in the interview study, many siblings reported that cancer had been important in the formation of positive aspects of their personality, and in predisposing them to developing psychological problems. Furthermore, although cancer was in the past, many of them still thought about cancer very regularly, highlighting the importance of studying the continued impact on siblings’ lives.

Secondly, this study was based in New Zealand: This is only the second project to study siblings in New Zealand, and appears to have identified an increased risk that siblings in New Zealand face relative to their overseas counterparts on the basis of higher depression scores, with 76% over the cut-off score on the depression scale used. Wellbeing and self-esteem scores did not show any differences from what was expected from a general population.

Thirdly, this study addressed more than one or two aspects of psychological adjustment, including measures of positive adjustment (self-esteem), negative adjustment (depression) and global adjustment (wellbeing). In examining correlations and regressions, parental differential treatment and peer relationships predicted depression, but not self-esteem or wellbeing, and the sibling relationships predicted wellbeing and self-esteem, but not depression. The difference in patterns of predictors reinforces the importance of broadening our understanding of siblings’ adjustment beyond one or two narrowly defined constructs.

Finally, the impact of optimism, parental differential treatment, sibling warmth and conflict, and peer attachment was analysed. In terms of previous research with siblings of children with cancer, these variables have either not been examined, or been examined only in one or two studies. The findings in regards to these relationships are that: optimism is especially important for supporting adaptive psychological adjustment in this population; higher sibling warmth with the sibling who had cancer predicts decreased sibling wellbeing and self-esteem;
lack of parental attention relative to the sibling who had cancer, and parental differential treatment being perceived as unfair predicts depression, and peer alienation predicts depression.

In terms of the findings from the interview study, siblings in New Zealand tend to report similar issues as their overseas counterparts. They reported that cancer was stressful, and that many things stressed them out at the same time as cancer. They reported struggling with a lack of attention and jealousy of the excess attention on their sibling. They described an array of coping techniques which helped them to survive a difficult period in their life. They also talked about being involved in the cancer experience, and how this reduced the impact of parental differential treatment, and made it easier to cope with the uncertainty of not knowing what was happening.

All of them identified some sort of positive impact from cancer, regards to their own personal growth, their growth as a family, and having more opportunities to do things, as well as good memories. Finally, they discussed interactions with people outside the family, firstly the difficulties many of them had with a lack of understanding, and having people respond badly to knowing their sibling had cancer. However even from this they identified positive outcomes, in that they were able to build better deeper relationships with other people who had also faced adversity of some kind.

The results from this study may be useful to families and professionals working with families to increase understanding of how certain peer and family dynamics can impact on siblings. For example, the importance of encouraging siblings to maintain and build good relationships with peers may help reduce alienation, while simultaneously preventing an overly warm bond between siblings which has been linked to lower self-esteem and wellbeing.

This study has focused on recognising the needs and perspective of siblings in families where a child has cancer. It is important to acknowledge the difficulty parents and obviously the child with cancer also face. Recommendations to parents to reduce parental differential treatment, support siblings in developing self-esteem and identity outside of their sibling’s cancer, and to have open and supportive discussions may be very difficult to follow. Managing siblings’ adjustment is one of only many demands on the time of a parent of a child with cancer. The benefit of this research is that it has identified a number of things that have been related to positive and negative adjustment in siblings. It is hoped that this can be used to reduce the guesswork involved in knowing what might support the adaptive psychological adjustment of a sibling of a cancer survivor.
References


126


Patterson, P., Millar, B., & Visser, A. (2011). The development of an instrument to assess the unmet needs of young people who have a sibling with cancer: Piloting the sibling cancer...


Stocker, C. M. (1994). Children's perceptions of relationships with siblings, friends, and
mothers: Compensatory processes and links with adjustment. *Journal of Child


of childhood cancer survivors: How does this "forgotten" group of children adjust after
cessation of successful cancer treatment? *European Journal of Cancer, 31*(13-14), 2277-
2283. doi:10.1016/0959-8049(95)00475-0

sibling inventory of behavior. In *What Do Children Need to Flourish?* (pp. 203-219):
Springer.

the Body.* Online: Oxford University Press.


functioning self-report scales: Comparison of mothers' and children's reports. *Journal of
Nervous & Mental Disease, 168*(12), 736-740.

cancer experience from the perspective of siblings: A need to give them a voice. *Journal of
Pediatric Oncology Nursing, 22*(6), 305-319. doi:10.1177/1043454205278035


survivors in New Zealand.* (Unpublished Master's of Philosophy, Auckland University of
Technology).

## Appendices

<table>
<thead>
<tr>
<th>Appendix</th>
<th>Pages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Appendix A</td>
<td>134</td>
</tr>
<tr>
<td>Appendix B</td>
<td>136</td>
</tr>
<tr>
<td>Appendix C</td>
<td>148</td>
</tr>
<tr>
<td>Appendix D</td>
<td>155</td>
</tr>
<tr>
<td>Appendix E</td>
<td>159</td>
</tr>
<tr>
<td>Appendix F</td>
<td>160</td>
</tr>
<tr>
<td>Appendix G</td>
<td>165</td>
</tr>
</tbody>
</table>
Appendix A

Parent Questionnaire (Questionnaire study)
**Parent questionnaire**

We would like to ask a few questions about your family to help us better understand the responses your son or daughter may give on the main questionnaire.

For the son or daughter in remission or cured from cancer:

What is their age? : ____

What is their gender? : Male    Female

What is their ethnicity: New Zealand European/Pakeha   Maori   Other:___________________

On what date was this child diagnosed with cancer? (month/year) ______

On what date did the most recent treatment finish? (month/year)_____

What type of cancer did this child have? _____________________________________________

What treatment(s) did this child have? (circle all that apply):

Radiation   Chemotherapy   Surgery   Other:___________________

Number and approximate dates of relapses (if any): ___________________________________

How would you rate this child’s current health status from 1- 10 (1=Poor, 10=Excellent)___

For the son or daughter who did not have cancer and is completing the questionnaire:

How would you estimate this child’s current health status from 1- 10 (1=Poor, 10=Excellent)___

Did this child undergo any medical procedures in relation to their sibling’s cancer? (e.g. blood tests to check donor compatibility) Please give details (type and number of procedures):_____

General Questions: (please circle the response that is closest to true).

<table>
<thead>
<tr>
<th>In general, how would you describe the atmosphere within your home?</th>
<th>No tension</th>
<th>Some tension</th>
<th>A lot of tension</th>
</tr>
</thead>
<tbody>
<tr>
<td>If you live with a partner or spouse, do you and your partner work out arguments with:</td>
<td>No difficulty</td>
<td>Some difficulty</td>
<td>Great difficulty</td>
</tr>
<tr>
<td>How structured are the routines of the people in your home?</td>
<td>Unstructured</td>
<td>Somewhat structured</td>
<td>Very structured</td>
</tr>
</tbody>
</table>
Appendix B

Sibling Questionnaire (Questionnaire study)
We are interested in what YOU, as a brother or sister of someone who has finished treatment for cancer, have to say about your life and your relationships.

This questionnaire will ask you about your overall well-being, including your mood, and self-esteem. It will also ask about your relationship with your parents, your sibling and your friends.

All completed and returned questionnaires will go into a draw to win one of four $100 vouchers for a store of your choice.

Questionnaire instructions:
- The questionnaire is broken up into a number of smaller sections.
- Please complete all sections in the questionnaire. There may be specific instructions for different parts of the questionnaire.
- Most questions will have a choice of up to 6 responses, please circle ONE response for each question. Circle the answer that comes closest to describing you.
- If you change your mind, put an X through your original response and circle the new one.
- There are no right or wrong answers, just give your own thoughts. Don’t spend too long on any one question.
- At times the questions may seem repetitive, don’t worry, they have been specially designed to give the best results for our research.
- Remember – the whole questionnaire will take about 20 minutes to complete, but it doesn’t all have to be done at once. If you do take a break, try not to stop in the middle of a section.

Don’t forget: All of your answers are confidential

Please return the completed questionnaire by May 31st to be entered in the draw

All completed and returned questionnaires will go into a draw to win one of four $100 vouchers for a store of your choice

Thank you in advance for completing this survey.
Section 1:

Are you between the ages of 12 and 18? .................................................................Yes No
Do you have a sibling who has had treatment for cancer, but is not on treatment at the moment?...Yes No
At the moment, do you live with the brother or sister who is in remission or cured from cancer?......Yes No
Are you the only person in your family completing this questionnaire?.................................Yes No
Are you able to read and understand English?......................................................................Yes No
Have you completed the assent form for this study? (or consent form if you are over 16).........Yes No
If you are under 16 has your parent/guardian given you permission to complete this study? ..........Yes No

If you can answer YES to all the above questions please continue with the rest of the questionnaire.

If you answered NO to any of the questions I am afraid we cannot use your information for this survey.
Thank you for your co-operation. Please text, call or email the research team with any questions.

Section 2:

Name:_____________________________________________________________
Age: _____ Please circle: Male Female
Ethnicity: New Zealand European/Pakeha ;
          Maori
          Pacific Islander_____________________
          Other ethnicity (please specify) __________________________________________

Please list the ages and sex of ALL your brothers and sisters. Circle the one who had cancer (continue over the page if necessary).

Sibling #1: Age_____ Male/Female   Sibling #4: Age_____ Male/Female
Sibling #2: Age_____ Male/Female   Sibling #5: Age_____ Male/Female
Sibling #3: Age_____ Male/Female   Sibling #6: Age_____ Male/Female
Section 3

Who are the main adults who live with you and your brother(s)/sister(s)? Please write down their name and their relationship to you on the lines below (mum, step-father, grandma etc.).

If there is only one then please only fill in the first line,

If there are more than 2 choose the two people who look after you and your sibling(s) the most.

1) __________________________________________________________________________
2) __________________________________________________________________________

In this section, where it says #1 think about who you wrote on the first line just above (eg. Your Mum). Where it says #2 think of the person you wrote in the second line (eg. Your Dad).

Where it says “my sibling” think of the brother or sister with cancer.

Since your sibling stopped treatment:

<table>
<thead>
<tr>
<th></th>
<th>My sibling much more than me</th>
<th>My sibling a bit more than me</th>
<th>Both of us about the same</th>
<th>Me a bit more than my sibling</th>
<th>Me much more than my sibling</th>
</tr>
</thead>
<tbody>
<tr>
<td>1a</td>
<td>Who has #1 been most strict with?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Do you think #1’s behaviour here is fair?</td>
<td>Fair</td>
<td>Unfair</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1b</td>
<td>Who has #2 been most strict with?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Do you think #2’s behaviour here is fair?</td>
<td>Fair</td>
<td>Unfair</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2a</td>
<td>Who has #1 been most proud of for doing things?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Do you think #1’s behaviour here is fair?</td>
<td>Fair</td>
<td>Unfair</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2b</td>
<td>Who has #2 been most proud of for doing things?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Do you think #2’s behaviour here is fair?</td>
<td>Fair</td>
<td>Unfair</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3a</td>
<td>Who has #1 most enjoyed doing things with?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Do you think #1’s behaviour here is fair?</td>
<td>Fair</td>
<td>Unfair</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3b</td>
<td>Who has #2 most enjoyed doing things with?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Do you think #2’s behaviour here is fair?</td>
<td>Fair</td>
<td>Unfair</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4a</td>
<td>Whose thoughts and feeling has #1 been most sensitive to?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Do you think #1’s behaviour here is fair?</td>
<td>Fair</td>
<td>Unfair</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4b</td>
<td>Whose thoughts and feeling has #2 been most sensitive to?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Do you think #2’s behaviour here is fair?</td>
<td>Fair</td>
<td>Unfair</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5a</td>
<td>Who has #1 punished most for misbehaving?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Do you think #1’s behaviour here is fair?</td>
<td>Fair</td>
<td>Unfair</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Question</td>
<td>Rating Options</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>---------------------------------------------</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Who has #2 punished most for misbehaving?</td>
<td>1   2   3   4   5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you think #2’s behaviour here is fair?</td>
<td>Fair Unfair</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Who has #1 shown the most interest in the things you like to do?</td>
<td>1   2   3   4   5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you think #1’s behaviour here is fair?</td>
<td>Fair Unfair</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Who has #2 shown the most interest in the things you like to do?</td>
<td>1   2   3   4   5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you think #2’s behaviour here is fair?</td>
<td>Fair Unfair</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Who has #1 blamed most for things other family members did?</td>
<td>1   2   3   4   5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you think #1’s behaviour here is fair?</td>
<td>Fair Unfair</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Who has #2 blamed most for things other family members did?</td>
<td>1   2   3   4   5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you think #2’s behaviour here is fair?</td>
<td>Fair Unfair</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Who has #1 tended to favour?</td>
<td>1   2   3   4   5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you think #1’s behaviour here is fair?</td>
<td>Fair Unfair</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Who has #2 tended to favour?</td>
<td>1   2   3   4   5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you think #2’s behaviour here is fair?</td>
<td>Fair Unfair</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Who has #1 disciplined most?</td>
<td>1   2   3   4   5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you think #1’s behaviour here is fair?</td>
<td>Fair Unfair</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Who has #2 disciplined most?</td>
<td>1   2   3   4   5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you think #2’s behaviour here is fair?</td>
<td>Fair Unfair</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Section 4

<table>
<thead>
<tr>
<th>Statement</th>
<th>Rating Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. In uncertain times, I usually expect the best.</td>
<td>strongly disagree disagree neutral agree strongly agree</td>
</tr>
<tr>
<td>2. It's easy for me to relax.</td>
<td>0   1   2   3   4</td>
</tr>
<tr>
<td>3. If something can go wrong for me, it will.</td>
<td>0   1   2   3   4</td>
</tr>
<tr>
<td>4. I always look on the bright side of things.</td>
<td>0   1   2   3   4</td>
</tr>
<tr>
<td>5. I'm always optimistic about my future.</td>
<td>0   1   2   3   4</td>
</tr>
<tr>
<td>6. I enjoy my friends a lot.</td>
<td>0   1   2   3   4</td>
</tr>
<tr>
<td>7. It's important for me to keep busy.</td>
<td>0   1   2   3   4</td>
</tr>
<tr>
<td>8. I hardly ever expect things to go my way.</td>
<td>0   1   2   3   4</td>
</tr>
<tr>
<td>9. Things never work out the way I want them to.</td>
<td>0   1   2   3   4</td>
</tr>
<tr>
<td>10. I don't get upset too easily.</td>
<td>0   1   2   3   4</td>
</tr>
<tr>
<td>11. I'm a believer in the idea that &quot;every cloud has a silver lining.&quot;</td>
<td>0   1   2   3   4</td>
</tr>
<tr>
<td>12. I rarely count on good things happening to me.</td>
<td>0   1   2   3   4</td>
</tr>
</tbody>
</table>
Section 5

During the past week...:

1. I was bothered by things which don’t usually bother me.
2. I did not feel like eating, /I wasn’t very hungry.
3. I wasn’t able to feel happy, even when my family or friends tried to help me feel better.
4. I felt like I was just as good as other kids.
5. I felt like I couldn’t pay attention to what I was doing.
6. I felt down and unhappy.
7. I felt like I was too tired to do things.
8. I felt like something good was going to happen.
9. I felt like things I did before didn’t work out right.
10. I felt scared.
11. I didn’t sleep as well as I usually sleep.
12. I was happy.
13. I was more quiet than usual.
14. I felt lonely, like I didn’t have any friends.
15. I felt like kids I know were not friendly or that they didn’t want to be with me.
16. I had a good time.
17. I felt like crying.
18. I felt sad.
19. I felt people didn’t like me.
20. It was hard to get started doing things.

Section 6

1. I like to get my friends' point of view on things I'm concerned about.
2. My friends sense when I'm upset about something.
3. When we discuss things, my friends consider my point of view.
4. Talking over my problems with my friends makes me feel ashamed or foolish.
5. I wish I had different friends.
6. My friends understand me.
7. My friends encourage me to talk about my difficulties.
8. My friends accept me as I am.
9. I feel the need to be in touch with my friends more often.
10. My friends don't understand what I'm going through these days.
11. I feel alone or apart when I am with my friends.
12. My friends listen to what I have to say.  
13. I feel my friends are good friends.  
14. My friends are fairly easy to talk to.  
15. When I am angry about something, my friends try to be understanding.  
16. My friends help me to understand myself better.  
17. My friends are concerned about my well-being.  
18. I feel angry with my friends.  
19. I can count on my friends when I need to get something off my chest.  
20. I trust my friends.  
22. I get upset a lot more than my friends know about.  
23. It seems as if my friends are irritated with me for no reason.  
24. I tell my friends about my problems and troubles.  
25. If my friends know something is bothering me, they ask me about it.

Section 7:
In this section, where it says “your sibling” think of the brother or sister who has/had cancer.

Some siblings do nice things for each other a lot, while other siblings do nice things for each other a little. How much do you and your sibling do nice things for each other?  
Some siblings care about each other a lot while other siblings don’t care about each other that much. How much do you and this sibling care about each other?  
How much do you and this sibling go places and do things together?  
How much do you and this sibling insult and call each other names?  
How much do you and this sibling like the same things?  
How much do you and this sibling tell each other everything?  
Some siblings try to out-do, or beat each other at things a lot, while other siblings try to out-do each other a little. How much do you and this sibling try to out-do each other at things?  
How much do you admire and respect this sibling?  
How much does this sibling admire and respect you?
<table>
<thead>
<tr>
<th></th>
<th>Hardly at all</th>
<th>Not too much</th>
<th>Somewhat</th>
<th>Very much</th>
<th>Extremely much</th>
</tr>
</thead>
<tbody>
<tr>
<td>How much do you and this sibling disagree and quarrel with each other?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some siblings cooperate a lot, while other siblings cooperate a little. How much do you and this sibling cooperate with other?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How much do you and this sibling love each other?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some siblings play around and have fun with each other a lot, while other siblings play around and have fun with each other a little. How much do you and this sibling play around and have fun with each other?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How much are you and this sibling mean to each other?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How much do you and this sibling have in common?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How much do you and this sibling share secrets and private feelings?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How much do you and this sibling compete with each other?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How much do you look up to and feel proud of this sibling?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How much does this sibling look up to and feel proud of you?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How much do you and this sibling get mad at and get in arguments with each other?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How much do both you and your sibling share with each other?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How much is there a strong feeling of affection (love) between you and this sibling?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some kids spend lots of time with their siblings, while others don’t spend so much. How much free time do you and this sibling spend together?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How much do you and this sibling bug and pick on each other in mean ways?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How much are you and this sibling alike?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How much do you and this sibling tell each other things you don’t want other people to know?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How much do you and this sibling try to do things better than each other?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How much do you think highly of this sibling?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How much does this sibling think highly of you?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How much do you and this sibling argue with each other?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Section 8:

Below is a list of statements dealing with your general feelings about yourself. If you strongly agree, circle SA, if you agree with the statement, circle A, if you disagree circle D, if you strongly disagree, circle SD.

1. I feel that I'm a person of worth, at least on an equal plane with others.  
2. I feel that I have a number of good qualities.  
3. All in all, I am inclined to feel that I am a failure.  
4. I am able to do things as well as most other people.  
5. I feel I do not have much to be proud of.  
6. I take a positive attitude toward myself.  
7. On the whole, I am satisfied with myself.  
8. I wish I could have more respect for myself.  
9. I certainly feel useless at times.  
10. At times I think I am no good at all.

Section 9:

During the past four (4) weeks how often did you and your family.....

1. Let each other know you really care about each other.  
2. Get angry with each other.  
3. Dislike each other’s ideas  
4. Shout at each other because you were upset with each other.  
5. Act lovingly and affectionately towards each other.  
6. Let each other know that you appreciate each other’s ideas or the things you do.  
7. Help each other do something that was important to them.  
8. Argue with each other when you disagree about something.  
9. Act supportive and understanding towards each other.
### Section 10:

<table>
<thead>
<tr>
<th></th>
<th>Statement</th>
<th>Strongly disagree</th>
<th>Moderately disagree</th>
<th>Slightly disagree</th>
<th>Slightly agree</th>
<th>Moderately agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>I tend to be influenced by people with strong opinions.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>2</td>
<td>In general, I feel I am in charge of the situation in which I live.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>3</td>
<td>I think it is important to have new experiences that challenge how you think about yourself and the world.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>4</td>
<td>Maintaining close relationships has been difficult and frustrating for me.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>5</td>
<td>I live life one day at a time and don't really think about the future.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>6</td>
<td>When I look at the story of my life, I am pleased with how things have turned out.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>7</td>
<td>I have confidence in my opinions, even if they are contrary to the general consensus.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>8</td>
<td>The demands of everyday life often get me down.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>9</td>
<td>For me, life has been a continuous process of learning, changing, and growth.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>10</td>
<td>People would describe me as a giving person, willing to share my time with others.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>11</td>
<td>Some people wander aimlessly through life, but I am not one of them.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>12</td>
<td>I judge myself by what I think is important, not by the values of what others think is important.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>13</td>
<td>I am quite good at managing the many responsibilities of my daily life.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>14</td>
<td>I like most aspects of my personality.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>15</td>
<td>I gave up trying to make big improvements or changes in my life a long time ago.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>16</td>
<td>I have not experienced many warm and trusting relationships with others.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>17</td>
<td>I sometimes feel as if I've done all there is to do in life.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>18</td>
<td>In many ways, I feel disappointed about my achievements in life.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
</tbody>
</table>

Thank you for participating in this survey, we really appreciate it! All completed questionnaires will go into a draw to win one of four $100 vouchers for a store of your choice! If you are interested in potentially taking part in a follow up interview please keep reading....
After we have got all the questionnaires back and have analysed the results, we want to tell you what we found and get your thoughts on our findings.

This will give you an opportunity to meet face to face with our main researcher (Eleanor Riddick/ Ele) and talk about what it was like for YOU during the cancer treatment, and since your brother or sister has gone into remission. You’ll have a chance to tell us about what helped you through that tough time and what things made it even tougher.

We will feedback our findings to the organisations that work with families like yours, in the hope that they can further understand what it is like to be a brother or sister of someone who has had cancer.

If you are selected by our research team for the interview you will receive a **$10 voucher** of your choice to thank you for your time (from a selection including book vouchers, Westfield malls, petrol and more!).

If you are interested, please tick the box below and leave us your contact details.

□ I am interested in potentially taking part in a 1 hour follow-up discussion and receiving more information about this. (Note: ticking the box now does not commit you to taking part; you can always change your mind later.)

□ I am NOT interested in taking part in a one hour follow-up discussion. Please remove me from your mailing list.

Please give your updated contact details if you are willing to participate in a follow-up interview (Note: the interview may not take place until up to 18 months after returning the questionnaire).

| Name:_____________________________________________________________ |
| Address:_____________________________________________________________ |
| _______________________________________________________________ |
| Phone number:______________________________________________________ |
| Email address:_______________________________________________________ |
| Another contact number is (e.g. mobile):_______________________________ |
The research teams contact details:

**Eleanor Riddick** – Principal Investigator
Email: erid006@aucklanduni.ac.nz

**Dr. Elizabeth Peterson (PhD)** – Supervisor: 09 373 7599 extn 89693
Email: e.peterson@auckland.ac.nz

Additional sources of support:

**CanTeen:** Is a support service for 13-24 year old cancer patients and their siblings:

www.Canteen.org.nz
0800 CANTEEN (0800 226 8336)

**Child Cancer Foundation:** Provides ongoing practical, emotional and financial assistance to children with cancer, and their families.

www.childcancer.org.nz
0800 4 CHILD (0800 4 24453)

**WHATSUP:** is a free, professional telephone counselling service for anyone in Aotearoa New Zealand aged between 5 and 18 years.

0800 WHATSUP (0800 942 8787)

**YOUTHLINE:** provides a whole range of services designed for young people.

Helpline: 0800 37 66 33
Free TXT: 234
Email/MSN: talk@youthline.co.nz

**Supersibs:** Is an organization that supports siblings of children and young people with cancer in the United States and Canada. Some of the information on this website may not be relevant to siblings in New Zealander because of different healthcare systems and school systems; however some of the information on the website may still be of interest.

http://www.supersibs.org/index.html
Appendix C

Sibling Participant Information Sheets (Questionnaire study)

Parent Information Sheets (Questionnaire study)
Hi,

My name is Eleanor Riddick (Ele). I am a Doctoral student at the University of Auckland studying Clinical Psychology. This information sheet is an outline of the study I am doing with 12 to 18 year olds who have a brother or sister in remission or cured from cancer. You have been sent this sheet because either you or your parent/guardian has said they are interested in taking part in this study.

We are looking at 12 to 18 year old brothers and sisters of children and young people who are in remission or cured from cancer. I believe recovery from a serious illness like cancer involves not just physical health, but well-being of the patient and their whole family. The results of this project may help those organizations who work with you and your family to support you throughout the cancer experience.

The full title of my project is: *Siblings of young people who are in remission or cured from cancer: A family systems approach to child-cancer.*

The aims of the study are:

- To gain insight into the points of view of 12 to 18 year old siblings of children and young people who are cured from, or in remission from cancer.
- To explore a range of things which might predict the general well being of siblings (for example: personality; age and spacing of siblings in your family; and relationships with friends and family).
- To explore the reasons siblings give for high or low levels of general well being.
- To use the data gathered to identify “at-risk siblings”

What’s involved:

You will be asked to:

- Complete a confidential questionnaire which asks about the relationships you have with your parents, with your sibling who has had cancer and with your peers. The questionnaire also measures mood, optimism, self-esteem, and general wellbeing. The questionnaire requires the ability to read and understand English and will take approximately 20 minutes to complete.
- The final page of the questionnaire will ask if you are willing to be contacted again later to have a face-to-face interview to discuss the findings from the survey. Further information will be supplied if you are selected for this part of the study.

Your parent/guardian will:

- Fill in a short confidential questionnaire which asks about the health and relationships of people in your family, mostly about you, and about your brother or sister with cancer.
- If you are under the age of 16, your parent/guardian may have already completed their part of the study, including giving consent to for you to take part.
If you decide you would like to complete this questionnaire, the questionnaire booklet sent with this information sheet can be filled out when it suits you and returned in the postage-paid envelope supplied by the 31st of May 2011.

All of the information and responses made by yourself and your parent/guardian will be confidential. Your parents will not be able to find out what you said, and you will not be able to find out what your parents said. I will write about my findings as part of my university degree (Doctorate) and I may publish some of my findings in scientific journals. Summary reports will also be made available to relevant health and education organisations, and to participants. None of these will contain specific information about you or your parent/guardian that could allow you to be identified.

Your participation is entirely voluntary (your choice). You do not have to take part in the study. However if you do take part you will be entered into a draw for one of four $100 prizes for a voucher of your choice. If you do agree to take part you still may change your mind at any time without giving a reason and you may withdraw information that you have provided at any time before the 31st of May 2011.

Data will be stored in a password-protected database on a password-protected computer and in a locked cabinet in a locked office at the University of Auckland. The data will be deleted or shredded after 14 years. Only the researcher and her supervisors will have access to the data.

Although this questionnaire does not ask directly about your experiences as a sibling of a child with cancer, it may lead you to think about this experience. There are no known risks associated with this study, but there is a chance that you may get upset by the subject. Telephone numbers for 24-hour support services are provided at the end of the questionnaire as well as website addresses of internet resources for siblings of children with serious illnesses. In the unusual circumstance that you experience severe emotional distress, there will be a list of psychology counselling resources provided and we encourage you to make contact.

The findings of this research may be useful for helping siblings of children/young-people with cancer in the future. Results will be made available to organisations that you and your family may have contact with, such as CanTeen, the Child Cancer Foundation, and Camp Quality. This may assist them in their work of supporting families of children and young people with cancer. At the completion of the study, a report of our findings will be made available to all participants and we would encourage you to contact us if you would like to discuss our findings or have any questions.

If you have any questions now about this study or would like more information please feel free to contact any member of the research team.

If you have any queries or concerns regarding your rights as a participant in this study, you may wish to contact an independent health and disability advocate:
Free phone: 0800 555 050
Free fax: 0800 2 SUPPORT (0800 2787 7678)
Email: advocacy@hdc.org.nz

Yours sincerely

Ele
The research teams contact details:

**Eleanor Riddick** (Ele) – Principal Investigator
Email: erid006@aucklanduni.ac.nz

**Dr. Elizabeth Peterson (PhD)** – Supervisor: 09 373 7599 extn 89693
Email: e.peterson@auckland.ac.nz

**Additional sources of support:**

**CanTeen:** Is a support service for 13-24 year old cancer patients and their siblings:
www.Canteen.org.nz
0800 CANTEEN (0800 226 8336)

**Child Cancer Foundation:** Provides ongoing practical, emotional and financial assistance to children with cancer, and their families.
www.childcancer.org.nz
0800 4 CHILD (0800 4 24453)

**WHATSUP:** is a free, professional telephone counselling service for anyone in Aotearoa New Zealand aged between 5 and 18 years.
0800 WHATSUP (0800 942 8787)

**YOUTHLINE:** provides a whole range of services designed for young people.
Helpline: 0800 37 66 33
Free TXT: 234
Email/MSN: talk@youthline.co.nz

**Supersibs:** Is an organization that supports siblings of children and young people with cancer in the United States and Canada. Much of the information on this website may not be relevant to siblings in New Zealand because of different healthcare and school systems; however some of the information on the website may still be of interest.
http://www.supersibs.org/index.html

This study has received ethical approval from the Multi-region Ethics Committee, which reviews national and multi-regional studies, ethics reference number: MEC/10/05/046
Parent / Guardian Information Sheet

Hi,
My name is Eleanor Riddick. I am a Doctoral student at the University of Auckland studying clinical Psychology. This information sheet outlines the study I am conducting with 12-18 year olds who have a brother or sister who has been discharged off treatment and is in remission or cured from cancer. You have been sent this sheet because either you or one of your children has indicated an interest in participating in this study.

We are looking at adolescent siblings of children and young people, who have been off-treatment for 1month to 10 years or more. I take a holistic approach to health, believing that recovery from a serious illness means not just physical health, but psychological wellbeing of the patient and their whole family. A disease like cancer affects not only the patient, but everyone who comes into contact with them. For organisations which work with these young people and their families, adequate service provision requires knowledge of the impact of cancer on brothers and sisters. The results of this project may help them to enhance the support they provide to the entire family throughout the cancer experience.

The full title of my project is: *Siblings of young people who are in remission or cured from cancer: A family systems approach to child-cancer.*

The aims of the study are:

5. To gain insight into the perspectives of adolescent siblings of children and young people who are in remission or cured from cancer.
6. To explore a range of cognitive, demographic and psychosocial factors that predict the general well being of siblings using questionnaires and interviews
7. To explore the reasons siblings give for high or low levels of general wellbeing.
8. To use the data I gather to identify “at-risk siblings”

What’s involved:

As a parent you will be asked to:

- Fill in a short 1 page confidential questionnaire which asks about the clinical, demographic and relationship features of your family, in particular of your child who has had cancer, and the child/children who are participating in the study.
- Consent to your child taking part in this study if they are under the age of 16.

Your child will be asked to:

- Complete a confidential questionnaire which asks about the relationships they hold with their parents, with their sibling who has had cancer and with their peers. The questionnaire also measures mood, optimism, self-esteem, and general wellbeing. The questionnaire requires the ability to read and understand English and will take approximately 20 minutes to complete.
- The final page of the questionnaire will ask your child if they are willing to be contacted again later to have a face-to-face interview to discuss the findings from the survey. Further information will be supplied if your child is selected for this part of the study.

If your child is under the age of 16, a pack including the questionnaire booklets and a sibling participant information sheet will be inside an A5 envelope in the package that has been sent to you, please pass this envelope and its contents on to them after you have signed the consent form. You and your child can then complete your sections independently and have each been provided with postage-paid envelopes to return the questionnaires no later than May 31st 2011. If your child is aged 16-18 and indicated interest in the
study themselves, a questionnaire booklet may have already been sent to them. For statistical reasons, only one child per family can participate.

All of the information and responses made by yourself and your child will be confidential. The data will be reported in a doctoral thesis prepared by Eleanor Riddick and in reports published in scientific journals. Summary reports will also be made available to relevant health and education organisations, and to participants. None of these will contain specific information about you or your child that could allow them to be identified.

Both your child’s and your participation is entirely voluntary (by choice). Neither of you have to take part in the study. However, if you both agree to participate, your child will be entered into a draw to win one of four $100 vouchers for a store of their choice. If you do agree, you can change your mind and stop your participation in any or all aspects of this study without giving a reason and you may withdraw any information you have provided up until May 31st 2011.

Data will be stored in a password-protected database on a password-protected computer and in a locked cabinet in a locked office at the University of Auckland. The data will be deleted and shredded after 14 years. Only the researcher and her supervisors will have access to the data.

Although the questionnaire does not ask directly about your child’s experiences as a sibling of someone with cancer, it may lead them to reflect on this experience. There are no known risks associated with this study, but there is a chance that your child may experience emotional distress bought on by this subject. Telephone numbers for 24-hour support services will be provided at the end of the questionnaire and this sheet, as well as web addresses of internet resources for siblings of children with serious illnesses. In the unusual circumstance that your child were to experience significant emotional distress, there will be a list of psychology counselling resources provided and we encourage you to make contact.

The findings of this research may be useful for helping siblings of children/young-people with cancer in the future. Results will be made available to organisations that you and your family may have contact with, such as CanTeen, the Child Cancer Foundation, and Camp Quality. This may assist them in their work of supporting families of children with cancer. At the completion of the study, a report of our findings will be made available to all participants and we would encourage you to contact us if you would like to discuss our findings or have any questions.

If you have any questions now about this study or would like more information please feel free to contact any member of the research team. Or if you have any queries or concerns regarding your rights as a participant in this study, you may wish to contact an independent health and disability advocate:

Free phone: 0800 555 050
Free fax: 0800 2 SUPPORT (0800 2787 7678)
Email: advocacy@hdc.org.nz

Yours sincerely
Eleanor
The research teams contact details:

Eleanor Riddick – Principal Investigator:
Email: erid006@aucklanduni.ac.nz

Dr. Elizabeth Peterson (PhD) – Supervisor: 09 373 7599 extn 89693
Email: e.peterson@auckland.ac.nz

Other resources that may be relevant to your child:

**CanTeen:** Is a support service for 13-24 year old cancer patients and their siblings:
www.Canteen.org.nz
0800 CANTEEN (0800 226 8336)

**Child Cancer Foundation:** Provides ongoing practical, emotional and financial assistance to children with cancer, and their families.
www.childcancer.org.nz
0800 4 CHILD (0800 4 24453)

**WHATSUP:** is a free, professional telephone counselling service for anyone in Aotearoa New Zealand aged between 5 and 18 years.
0800 WHATSUP (0800 942 8787)

**YOUTHLINE:** provides a whole range of services designed for young people.
Helpline: 0800 37 66 33
Free TXT: 234
Email/MSN: talk@youthline.co.nz

**Supersibs:** Is an organization that supports siblings of children and young people with cancer in the United States and Canada. Some of the information on this website may not be relevant to siblings in New Zealander because of different healthcare systems and school systems; however some of the information on the website may still be of interest.
www.supersibs.org

This study has received ethical approval from the Multi-region Ethics Committee, which reviews national and multi-regional studies, ethics reference number: MEC/10/05/046
Appendix D

Participant Consent Form (Questionnaire study)

Participant Assent Form (Questionnaire study)

Parental Consent Form (Questionnaire study)
Participant consent form

I have read and I understand the information sheet for volunteers taking part in the study on the wellbeing of adolescents who have a sibling who has survived cancer. I have had the opportunity to discuss this study and am satisfied with the answers I have been given.

I have had the opportunity to use Whanau/Family support or a friend to help me ask questions and understand the study.

I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time and this will not affect my future access to cancer-related family support.

I understand that my participation in this study is confidential and that I will not be named in any reports on this study.

I have had time to consider whether to take part and I know who to contact if I have any worries or questions about the study.

I understand if I complete the survey I go into a draw to win one of four $100 gift vouchers for a store of my choice.

I would like a copy of the research study once completed and written up. (Please note: there may be a long delay between data collection and publishing of the results).

__ Yes  __ No

The best address to send this to is:

Email:_________________________________________________________________

Home:_________________________________________________________________

I understand the data will be stored for 14 years then destroyed.

I ____________________________ (full name) hereby consent to take part in this study.

Date________________________

Signature______________________

Please contact us with any questions:

Eleanor Riddick – Principal Investigator
Email: erid006@aucklanduni.ac.nz
University of Auckland
Dept of Psychology TAMAKI campus
Private Bag 92019, Auckland.

Dr. Elizabeth Peterson (PhD) – Supervisor: 09 373 7599 extn 89693
Email: e.peterson@auckland.ac.nz
**Assent Form**

I have read and I understand the information sheet for volunteers taking part in the study on the wellbeing of 12 to 18 year olds who have a sibling who has survived cancer. I have had the opportunity to discuss this study and am satisfied with the answers I have been given.

I have had the opportunity to use Whanau/Family support or a friend to help me ask questions and understand the study.

I understand that taking part in this study is voluntary (my choice and my parent’s choice) and that we may withdraw from the study at any time and this will not affect our future access to cancer-related family support.

I understand that my participation in this study is confidential and that I will not be named in any reports on this study.

I understand if I complete the survey I go into a draw to win one of four $100 gift vouchers for a store of my choice.

I have had time to consider whether to take part and I know who to contact if I have any worries or questions about the study.

I would like a copy of the research results once completed and written up. (Please note: there may be a long delay between data collection and publishing of the results).

__ Yes __ No

The best address to send this to is:

Email: ____________________________________________

Home: ____________________________________________

I understand the data will be stored for 14 years then destroyed.

I ______________________________ (full name) hereby consent to take part in this study.

Date_________________________

Signature__________________________________

**Please contact us with any questions:**
**Eleanor Riddick** – Principal Investigator
Email: erid006@aucklanduni.ac.nz
University of Auckland
Dept of Psychology TAMAKI campus
Private Bag 92019
Auckland.

**Dr. Elizabeth Peterson (PhD)** – Supervisor: 09 373 7599 extn 89693
Email: e.peterson@auckland.ac.nz
Parent/Guardian Consent Form

I have read and understood the parent/guardian information sheet. I have had the opportunity to ask questions about this study and am satisfied with the answers I have been given. I have had the opportunity to use Whanau/Family support or a friend to help me ask questions and understand the study.

I understand that taking part in this study is voluntary (my choice and my child’s choice) and that we may withdraw from the study at any time before September 9th and this will not affect our future access to cancer-related family support.

I understand that participation in this study is confidential and that no material which could identify me or my child will be used in any reports on this study.

I have had time to consider whether to take part and I know who to contact if I have any concerns or questions about the study.

I understand the data will be stored for 14 years then destroyed.

I consent to take part in this study by completing the parent questionnaire.................yes / no

Full name:
Son/daughter’s full name:
Date_________________________
Signature________________________________

Please contact us with any questions:
Eleanor Riddick – Principal Investigator
University of Auckland
Dept of Psychology TAMAKI campus
Private Bag 92019
Auckland.

Dr. Elizabeth Peterson (PhD) – Supervisor: 09 373 7599 extn 89693
Email: e.peterson@auckland.ac.nz
Appendix E

Changes made to outliers with Z-scores higher than 2.58 (p<.01)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Case</th>
<th>Z-score</th>
<th>Original Value</th>
<th>Mean</th>
<th>SD</th>
<th>Changed to: Mean+/−2SDs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wellbeing</td>
<td>31</td>
<td>-3.59824</td>
<td>2.22</td>
<td>4.3582</td>
<td>.59362</td>
<td>3.17096</td>
</tr>
<tr>
<td>Optimism</td>
<td>31</td>
<td>-2.86376</td>
<td>1.00</td>
<td>2.3134</td>
<td>.45862</td>
<td>1.39616</td>
</tr>
<tr>
<td>Relative maternal affection</td>
<td>7</td>
<td>-2.85153</td>
<td>1.2</td>
<td>2.5357</td>
<td>.46842</td>
<td>1.59886</td>
</tr>
<tr>
<td>Relative maternal control</td>
<td>16</td>
<td>-3.11506</td>
<td>1.0</td>
<td>3.5045</td>
<td>.80398</td>
<td>1.89654</td>
</tr>
<tr>
<td>Relative parental affection</td>
<td>30</td>
<td>2.81381</td>
<td>3.80</td>
<td>2.6935</td>
<td>.39322</td>
<td>3.47994</td>
</tr>
<tr>
<td>Relative parental control</td>
<td>16</td>
<td>-2.85068</td>
<td>1.38</td>
<td>3.4234</td>
<td>.71856</td>
<td>1.98628</td>
</tr>
<tr>
<td>Peer trust</td>
<td>30</td>
<td>-3.16437</td>
<td>10</td>
<td>39.7806</td>
<td>9.41122</td>
<td>20.95816</td>
</tr>
</tbody>
</table>
Appendix F

Participant Information Sheet (Interview study)

Parent Information Sheet (Interview study)
Participant Information Sheet

Brothers and Sisters of cancer survivors Interview

As you have already completed the questionnaire either by post or online, you are aware of the main elements of the study I am conducting with 12 to 18 year olds who have a brother or sister in remission or cured from cancer. Thank you so much for taking the time to fill this in, and for indicating an interest in participating in a follow-up interview.

The interview will take approximately one hour, and will take place in a private room with only the interviewer (Ele Riddick) and yourself present. Interviews will be recorded using a voice recorder, and with your permission the interview content will be transcribed by a university approved professional transcriber. To thank you for your participation in the study, you will be given a $10 voucher.

Topics covered in the interview will include family, cancer, and personal wellbeing among other topics that you might want to talk about.

As with the questionnaire, all of the information gathered through the interview will be confidential. Except in the case of safety concerns, particularly risk of harm to self or others, information shared in the interview will not be shared with your parents or others outside of the research team without your permission. If we feel a need to discuss anything with your parents we would endeavour to discuss this with you first.

Participation in interviews is voluntary. If you decide during or after an interview that you do not want your interview to be included in the analysis you can change your mind without giving a reason and can withdraw information within 2 weeks of the interview by contacting me through the contact details below.

When the overall conclusions are written up, any quotes or specific details included in the write-up will not be accompanied by information allowing you to be identified. Transcripts and audio files will be stored in a password-protected database on a password-protected computer and in a locked filing-cabinet in a locked office at the University of Auckland. The data will be deleted or shredded after 14 years. Only the researcher and her supervisors will have access to the data.

It is possible that some participants may find the subject matter upsetting. Telephone numbers for 24-hour support services are provided on the back of this information sheet. If you find the interview especially distressing we will your parents the contact details of a clinical psychologist who can talk to you and your parents about the possibility of a referral for counselling or other means of support.

If you have any questions now about this study or would like more information please feel free to contact any member of the research team.

If you have any queries or concerns regarding your rights as a participant in this study, you may wish to contact an independent health and disability advocate:
Free phone: 0800 555 050, Free fax: 0800 2787 7678
Email: advocacy@hdc.org.nz

Yours sincerely

Ele
The research teams contact details:

**Eleanor Riddick (Ele) – Principal Investigator**
Email: erid006@aucklanduni.ac.nz

**Dr. Elizabeth Peterson (PhD) – Supervisor: 09 373 7599 extn 89693**
Email: e.peterson@auckland.ac.nz

**Additional sources of support:**

**CanTeen:** Is a support service for 13-24 year old cancer patients and their siblings:
- 0800 CANTEEN (0800 226 8336)

**Child Cancer Foundation:** Provides ongoing practical, emotional and financial assistance to children with cancer, and their families.
- [www.childcancer.org.nz](http://www.childcancer.org.nz)
- 0800 4 CHILD (0800 4 24453)

**WHATSUP:** is a free, professional telephone counselling service for anyone in Aotearoa New Zealand aged between 5 and 18 years.
- 0800 WHATSUP (0800 942 8787)

**YOUTHLINE:** provides a whole range of services designed for young people.
- Helpline: 0800 37 66 33
- Free TXT: 234
- Email/MSN: talk@youthline.co.nz

**Supersibs:** Is an organization that supports siblings of children and young people with cancer in the United States and Canada. Much of the information on this website may not be relevant to siblings in New Zealand because of different healthcare and school systems; however some of the information on the website may still be of interest.
- [http://www.supersibs.org/index.html](http://www.supersibs.org/index.html)

This study has received ethical approval from the Multi-region Ethics Committee, which reviews national and multi-regional studies, ethics reference number: MEC/10/05/046
Parent Information Sheet

Brothers and Sisters of cancer survivors Interview

As you have already participated in the questionnaire part of the study I hope you are aware of the main elements of the study I am conducting with 12 to 18 year olds who have a brother or sister in remission or cured from cancer. Thank you so much for taking the time to fill that questionnaire in, and for giving consent for us to use your child’s responses. At the end of the questionnaire, your son/daughter indicated an interest in participating in a follow-up interview.

The interview will take approximately one hour, and will require a private un-interrupted space for myself and your son/daughter. Topics covered in the interview will include family, cancer, and personal wellbeing, among other relevant topics that your child might want to discuss. Interviews will be recorded using a voice recorder, and with your permission the interview content will be transcribed by a university approved professional transcriber. To thank your child for their participation in the study, they will be given a $10 voucher.

As with the questionnaire, all of the information gathered through the interview will be confidential between your child and the research team. Participants have been assured that information shared in the interview will not be passed on to their parents without their permission except in the case of safety concerns (e.g. risk of harm to self or others).

Participation in interviews is voluntary. If participants decide during or after an interview that they do not want their interview to continue, or do not want either the whole interview, or specific parts of the interview to be included in the analysis, they can withdraw information within 2 weeks of the interview by contacting me through the contact details below.

When the overall conclusions are written up, any quotes or specific details included will not be accompanied by information allowing the participant to be identified. Transcripts and audio files will be stored in a password-protected database on a password-protected computer and in a locked filing-cabinet in a locked office at the University of Auckland. The data will be deleted or shredded after 14 years. Only the researcher and her supervisors will have access to the data.

It is possible that some participants may find the subject matter upsetting. Telephone numbers for 24-hour support services are provided on the back of this information sheet. If your child finds the interview especially distressing we will offer you the contact details of a clinical psychologist who can talk to you and your child about the possibility of a referral for counselling or other means of support.

If you have any questions now about this study or would like more information please feel free to contact any member of the research team.

If you have any queries or concerns regarding your rights as a participant in this study, you may wish to contact an independent health and disability advocate:
Free phone: 0800 555 050, Free fax: 0800 2787 7678
Email: advocacy@hdc.org.nz

Yours sincerely

Ele
The research teams contact details:

**Eleanor Riddick** (Ele) – Principal Investigator
Email: erid006@aucklanduni.ac.nz

**Dr. Elizabeth Peterson (PhD)** – Supervisor: 09 373 7599 extn 89693
Email: e.peterson@auckland.ac.nz

Additional sources of support:

**CanTeen**: Is a support service for 13-24 year old cancer patients and their siblings:
www.Canteen.org.nz
0800 CANTEEN (0800 226 8336)

**Child Cancer Foundation**: Provides ongoing practical, emotional and financial assistance to children with cancer, and their families.
www.childcancer.org.nz
0800 4 CHILD (0800 4 24453)

**WHATSUP**: is a free, professional telephone counselling service for anyone in Aotearoa New Zealand aged between 5 and 18 years.
0800 WHATSUP (0800 942 8787)

**YOUTHLINE**: provides a whole range of services designed for young people.
Helpline: 0800 37 66 33
Free TXT: 234
Email/MSN: talk@youthline.co.nz

**Supersibs**: Is an organization that supports siblings of children and young people with cancer in the United States and Canada. Much of the information on this website may not be relevant to siblings in New Zealand because of different healthcare and school systems; however some of the information on the website may still be of interest.
http://www.supersibs.org/index.html

This study has received ethical approval from the Multi-region Ethics Committee, which reviews national and multi-regional studies, ethics reference number: MEC/10/05/046
Appendix G

Consent form (Interview study)

Assent form (Interview study)

Parent consent form (Interview study)
Appendix

Consent Form: Interview

I have read and I understand the information sheet for volunteers taking part in interviews for the “Brothers and Sisters of cancer survivors” research study. I have had the opportunity to discuss this study and am satisfied with the answers I have been given.

I have had the opportunity to use Whanau/Family support or a friend to help me ask questions and understand the study.

I understand that taking part in this study is voluntary (my choice) and that we may withdraw from the study at any time within two weeks of the interview and this will not affect our future access to cancer-related family support.

I understand that my participation in this study is confidential and that I will not be named in any reports on this study.

I understand if I complete the interview I will be given a $10 voucher.

I understand the data will be stored for 14 years then destroyed.

I consent to taking part in this study.................................................................Yes / No
I consent to having the interview recorded by a voice recorder........................................... Yes / No
I consent to the recording being transcribed by a university employed transcriber who is NOT part of the named research team. .................................................................Yes / No

Full name:__________________________________________________________

Date_____________________

Signature________________________________

Please contact us with any questions:

Eleanor Riddick – Principal Investigator
Email: erid006@aucklanduni.ac.nz
University of Auckland
Dept of Psychology TAMAKI campus
Private Bag 92019
Auckland.

Dr. Elizabeth Peterson (PhD) – Supervisor: 09 373 7599 extn 89693
Email: e.peterson@auckland.ac.nz
I have read and I understand the information sheet for volunteers taking part in interviews for the “Brothers and Sisters of cancer survivors” research study. I have had the opportunity to discuss this study and am satisfied with the answers I have been given.

I have had the opportunity to use Whanau/Family support or a friend to help me ask questions and understand the study.

I understand that taking part in this study is voluntary (my choice and my parent’s choice) and that we may withdraw from the study at any time within two weeks of the interview and this will not affect our future access to cancer-related family support.

I understand that my participation in this study is confidential and that I will not be named in any reports on this study.

I understand if I complete the interview I will be given a $10 voucher.

I understand the data will be stored for 14 years then destroyed.

I agree to take part in this study.................................................................Yes / No

I agree to having the interview recorded by a voice recorder.............................. Yes / No

I agree to the recording to be transcribed by a university employed transcriber who is NOT part of the named research team. ..............................................Yes / No

Full name:_______________________________________________

Date________________________

Signature__________________________________

Please contact us with any questions:
Eleanor Riddick – Principal Investigator
Email: erid006@aucklanduni.ac.nz
University of Auckland
Dept of Psychology TAMAKI campus
Private Bag 92019
Auckland.

Dr. Elizabeth Peterson (PhD) – Supervisor: 09 373 7599 extn 89693
Email: e.peterson@auckland.ac.nz
Parent/Guardian Consent Form: Interview

I have read and understood the information sheet for parents of participants taking part in interviews. I have had the opportunity to ask questions about this study and am satisfied with the answers I have been given. I have had the opportunity to use Whanau/Family support or a friend to help me ask questions and understand the study.

I understand that taking part in this study is voluntary (my choice and my child’s choice) and that we may withdraw from the study at any time within two weeks of the interview and this will not affect our future access to cancer-related family support.

I understand that participation in this study is confidential and that no material which could identify me or my child will be used in any reports on this study.

I have had time to consider whether to take part and I know who to contact if I have any concerns or questions about the study.

I understand the data will be stored for 14 years then destroyed.

I give consent for my son/daughter to take part in this interview........................................yes / no
I give consent for the interview to be recorded using a voice recorder............................yes / no
I give consent for the recording to be transcribed by a university employed transcriber who is NOT part of the named research team. ..............................................................yes / no

Full name:

Son/daughter’s full name:

Date________________________

Signature__________________________________

Please contact us with any questions:

Eleanor Riddick – Principal Investigator
University of Auckland
Dept of Psychology TAMAKI campus
Private Bag 92019
Auckland.

Dr. Elizabeth Peterson (PhD) – Supervisor: 09 373 7599 extn 89693
Email: e.peterson@auckland.ac.nz