

**Social support, coping strategies and the impact on relationships  
for adolescents who have experienced cancer.**

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## Abstract

Adolescence is a period characterised by a number of biological, social and psychological changes. Those facing a cancer diagnosis in adolescence find that they have further challenges and changes to deal with, in addition to the normal challenges associated with adolescence. The purpose of this research was to understand the experiences of adolescents who have had cancer. The aim was to examine the impact their illness had on their social relationships, to explore how they coped and found support, and to investigate the impact having cancer had on the developmental tasks associated with adolescence. While there has been extensive literature on these topics internationally, there has been limited research conducted within a New Zealand context. Semi-structured interviews were completed with eight young people who had been diagnosed with cancer between the ages of 13 and 20. These interviews were transcribed and analysed using thematic analysis. Two topics that seemed to encapsulate the overall experiences of the participants were identified. These topics were coping with cancer and life will never be the same. In addition, seven themes were identified, which included: coping strategies, the importance of social support, obtaining illness related information, cancer as loss, cancer as a time of growth and development, relationships change and after the cancer is gone. The findings of this study highlighted the importance of providing information for adolescents at the right time in their cancer journey. Another major finding in this study was that many young people with cancer felt that their peers were not equipped to deal with their illness or offer support, and as a result many relationships were lost. Despite this, many participants reported that they were able to utilise social support by meeting others with cancer and receiving support from parents, siblings and some peers. Another key finding from this study was that following the completion of treatment, adolescents continue to face a number of challenges. Some of these challenges include dealing with the long term effects of their illness such as infertility or learning to adjust to a new identity as a cancer survivor. While findings in this study suggested that cancer was conceptualised as a time of loss including a loss of identity and a loss of opportunities, all participants were able to identify positive changes as a result of their illness. These changes included a newfound appreciation for life and making the most of opportunities they were

provided. This thesis provides recommendations for professionals, agencies and services working with this population to ensure that appropriate emotional and psychological support is continued to be offered to young people and their families, particularly following completion of treatment. There was also a need identified for peers of young people with cancer to be given some sort of education in order to help support their peers through their cancer journey.

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# *Chapter One:*

## *Literature Review*

Adolescence is a developmental period characterised by a number of psychological and biological changes. For most adolescents, there are a number of issues to deal with including independent decision making and developing a positive self-image (Wicks & Mitchell, 2010). However, in addition, those who have experienced cancer face a variety of other challenges. These can include depending on others for support while simultaneously craving independence, decision making around risk-taking behaviors while taking into account their prior health concerns and dealing with the physical and psychological effects of the illness and medication side effects (Abrams, Hazen, & Penson, 2007; Allen, 1997; Coleman & Hendry, 1990). Adolescents with cancer also face a number of other challenges associated with their illness. These challenges can include disruption to normal life and school, dealing with peers and family, learning to understand the illness and adapting to balancing two identities, one as an adolescent and one as an adolescent with cancer (Decker, 2007).

### *Cancer in adolescence*

In most western countries, with the exception of motor vehicle accidents, suicide, or homicide, cancer is the leading cause of young adult mortality (Desandes et al., 2006; Wilkinson, Feltbower, Lewis, Parslow, & McKinney, 2001; Martos, Winther, & Olsen, 1993). Data from the National Cancer Institute's Surveillance, Epidemiology and End Result (SEER) programme suggested that during the 1990's in the United States, the prevalence of new cancer cases in those aged 15-19 was 203, per million, per year (Ries et al., 2006). Projections for the incidence of cancer in the United States in 2014 were 5330 new diagnoses and approximately 610 deaths of adolescents aged 15-19 (Ward, DeSentis, Robbins, Kohler & Jemal, 2014). Research by Cotterill and colleagues (2000) found that this rate is two-thirds higher than those aged 10-14 and twice as high as those aged 5-9. However, worldwide the proportion of cancer in those aged between 15 and 19 is only 0.5% of all cancer cases (Desandes, 2007).

The most common cancers associated with the adolescent period include Hodgkin's lymphoma, acute lymphoblastic leukaemia, acute myeloid leukaemia, tumours of the central nervous system, soft tissue and bone sarcomas and germ cell tumours such as testicular cancer (Barr, 2007; Desandes, 2007). Studies have found prognosis of cancer in young people to be relatively good; for example, the five year survival rate for all cancers in adolescence is 73% in Europe (Clavel, Steliarova-Foucher, Berger, Danon, & Valerianova, 2006) and 78% in the United States (Ries et al., 2006). However, these rates do vary by type of cancer; for example, survival from Hodgkin's lymphoma is high (89-92%), while prognosis for chronic myeloid leukaemia is much lower (37%) (Ries et al., 2006).

With increasing rates of survival, research has sought to examine how a cancer diagnosis affects young people during their illness and following recovery. For the purpose of research regarding cancer and young people, most studies use a definition of childhood cancer as those affecting people 14 and under, while adolescent cancer is defined as affecting those between 15 and 19 (Barr, 1999). Palmer and colleagues (2007) suggest that adolescents with cancer pose a challenge to the health system, which is usually split into paediatric or adult care. Adolescents form a distinct group, where they no longer fit with the family-centred youth approach and are not quite at the age to benefit from the individualised style of the adult cancer service. Similarly, Taylor (1999) asserted that providing adequate psychosocial care for semi-independent adolescents is more complex than for children who are more dependent on their parents. Taylor (1999) posits that adolescents' cancer care can be more demanding, because in addition to dealing with their illness, they are also exploring areas such as sexuality and risk taking behaviours such as substance use, similar to their healthy peers. Therefore, it is imperative that those working with adolescents address these issues, which may be ignored in paediatric units. As a result, in the United Kingdom, there has been a shift to develop teenage units and units for young people dealing with cancer.

A study by Debrack et al. (2013) examined the extent to which young adults with cancer felt their emotional, informational and practical support needs were met while being treated in either paediatric or adult oncology settings. This

study was conducted by sending surveys to 215 adolescents and young adults (99 from pediatric units and 116 from adult care services) who had been diagnosed with cancer within the past four months. Debrack and colleagues found that compared to teenagers who were in pediatric units, adolescents and young adults who were in adult services were more likely to report that they felt they did not receive information on age-appropriate internet websites, professional mental health services, information on camps and alternative health services. Palmer and colleagues (2007) also acknowledged that it has been only recently that there has been a focus on the provision of services for adolescents with cancer. Palmer et al. posit that areas of concern that have been identified for this age group include a “delay in diagnosis, lack of age-appropriate information, exclusion from decision making, keeping up with education, being in close proximity to other young people with similar conditions, and communication with medical staff” (p. 128). This finding supports the developments in the United Kingdom which aimed to better meet the needs of young people who may find it difficult to find an age appropriate service.

A report by the New Zealand Ministry of Health (2009) commented on the services provided by the Adolescent and Young Adult (AYA) Service for Cancer in New Zealand. Their mission is to link multi-disciplinary teams, a AYA key worker and psychosocial services to ensure the young person with cancer has a seamless journey. The report describes that the aim of the service is to meet the specific needs of the adolescents and young people by partnering both pediatric and adult cancer services. According to the report, this ensures young people are given age appropriate diagnosis and treatment which is aligned with the needs of young people with cancer as identified by Palmer and colleagues (2007). In addition, the AYA service has a focus on providing access to psychosocial services including social work, education, psychology, mental health services and youth support services in the community such as CanTeen, employment, and support in the home. This report on the AYA service also emphasises the need for assessment of psychological well-being following treatment, which focuses on issues specifically relevant to adolescents, including family support, drug and alcohol use, education and employment.

The teen not only has to deal with the diagnosis of cancer, but also there are a number of adverse physical and medical side effects from cancer treatments;

these can include pain, nausea, fatigue, mouth sores and an increased risk of infection or anaemia (Albano & Odom, 1993; Hedstrom, Haglund, Skolin, & von Essen, 2003). Hedstrom et al. (2003) interviewed adolescents with cancer, and found they were most distressed by nausea, pain during their diagnostic procedures and treatments, and how their appearance would change. This is consistent with findings from a study by Hedstrom, Ljungman and von Essen (2005) examining types of distress experienced by adolescents four to eight weeks after diagnosis. These adolescents were most concerned with physical effects such as mucositis which is an inflammation of the digestive tract following chemotherapy and radiation, changes in weight, and fatigue. In addition, participants cited treatment related issues such as missing school and a reduced ability to participate in recreational activities as concerns.

Another important issue for many adolescents who have had cancer is the effect their treatment may have had on their fertility. A review by Schover (2005) emphasised that for both men and women there is considerable distress if they are told that they may never be able to have children. For some young females, being told they were infertile was just as distressing as being initially told that they had cancer (Schover, 2005). Oosterhuis et al. (2008) examined issues relating to fertility in cancer patients by surveying 97 parents of paediatric patients and 13 adolescent patients (14 years and older). This study found that approximately 43% of adolescent oncology patients were concerned their treatment might make them infertile. Implications of these findings include the importance for professionals to explain the possibility of infertility as a potential side effect and to provide adequate opportunities to address questions or concerns. Professionals should feel comfortable discussing possible alternatives such as adoption, third party reproduction or biological options if the young person wishes (Schover, 2005).

In addition to the physical side effects from the illness and treatment, there are a number of psychological and social effects of having cancer (Abrams, Hazen, & Penson, 2007; Allen, Newman, & Souhami, 1997; Bellizzi et al., 2012). With increased survivorship rates of adolescents who have been diagnosed with cancer, more research has focused on the long term impact of cancer on developmental processes and the possible psychological and social effects (Abrams, Hazen, & Penson, 2007; Madan-Swain et al., 1994).

*Psychosocial and psychological outcomes for adolescents with cancer*

Previous research examining long term psychosocial outcomes for adolescents who have experienced cancer have been varied and found conflicting results. There have been a number of studies that have suggested that experiencing cancer in adolescence can lead to a variety of adverse outcomes, including behavioural difficulties (Nathan et al., 2009; Gurney et al., 2009), learning difficulties (Upton & Eiser, 2006) and emotional problems (Hudson et al., 2003; Mulhern, Merchant, Gajjar, Reddick, & Kum, 2004). However, in contrast, studies conducted by Gray and colleagues (1992) and Kupst and colleagues (1995) found that those adolescents who had cancer had similar rates of depression to healthy controls. Some studies even suggest that those who have experienced cancer fare the same or even better than matched healthy controls in areas of psychological well being such as resilience and appreciation for life and relationships (Sundberg, Lampic, Bjork, Arvidson, & Wettergren, 2009).

A review by Abrams, Hazen and Penson (2007) examining psychosocial outcomes for adolescents with cancer suggested that these contradicting findings may be explained by the fact that an individual's level of distress during a cancer diagnosis can be influenced by a number of factors. For example, they surmise that risk factors for an increased level of distress for adolescents with cancer include parental role modelling of poor coping strategies, social and emotional problems prior to diagnosis, and a negative or depressive attributional style. In addition, research also suggests that the type of cancer can affect the psychological impact on an individual. A review by Butler and Mulhern (2005) found that cancers relating to the central nervous system have been found to be related to higher levels of distress. Proposed explanations include the increased effect of neurocognitive deficits and the increased degree of social difficulties experienced by individuals following treatment for this type of cancer (Butler & Mulhern, 2005).

A German study by Dieluweit and colleagues (2010) examined psychosexual and family outcomes of 820 adolescent cancer survivors. Results indicated that compared to healthy controls, female survivors were less likely to have achieved tasks associated with psychosexual development, such as having a

boyfriend. These adolescents also reported a significantly stronger desire to have children than people of the same age who had not experienced cancer. Male survivors were also more likely than age matched controls to still be living at home. These results were consistent with a similar study conducted in Sweden which found that young adults who had experienced cancer during adolescence were less likely than their healthy peers to be married and were also more likely than healthy controls to still be living at home (Stam, Grootenhuis & Last, 2004).

While receiving a diagnosis of cancer during adolescence can significantly disrupt or delay achieving developmental milestones, there is also the chance for positive experiences as result of the illness (Bellizzi, 2004). Numerous studies (e.g. Novakovic et al., 1996; Hedstrom, Skolin, & von Essen, 2004; Mattsson, Ringner, Ljungman, & von Essen, 2007) have sought to examine some of the positive outcomes of living through cancer during adolescence. Mattsson and colleagues (2007) interviewed 38 young people, two years after their cancer diagnosis and found a number of areas in which the young people believed the cancer had affected their life positively. Nineteen participants reported having a more positive outlook on life, with statements such as “You really appreciate day-to-day life and you appreciate all the small things more” (Mattsson et al., 2007, p.1006). Participants described how they tried to not let small problems irritate them as they once did and instead focused on taking advantage of all opportunities.

Other positive themes that emerged from the interviews included an increase in maturity, responsibility and self esteem, the knowledge and experience gained from learning about their illness, and how being involved with health care services has encouraged them to widen their perspectives to think about different careers and recreational activities (Mattsson et al., 2007). The positive experiences that have come from the participants’ experience of cancer have been linked to the concept of post-traumatic growth. Tedeschi, Park and Calhoun (1998) labelled post-traumatic growth as a concept that describes positive changes in an individual’s identity, goals and values following a traumatic event. Recent literature has examined this idea of positive growth following adverse events using a positive psychology approach (Sumalla, Ochoa & Blanco, 2009).

Post-traumatic growth is common amongst cancer survivors, and a review by Sumalla, Ochoa and Blanco (2009) posits that post-traumatic growth has also been found amongst people who have suffered from HIV/AIDs, people who have had strokes and heart attacks, and victims of sexual abuse and natural disasters. Tedeschi and Calhoun (1996) identified three broad areas in which positive change can occur following a struggle with a challenging situation or event. These include changes in one's self, changes to interpersonal relationships and a new perspective on life. The positive changes as discussed earlier and identified by Mattsson and colleagues (2007) are consistent with these categories of change following post-traumatic growth.

#### *Adolescence as a developmental period*

In a review examining the impact of cancer and the adolescent period, Whyte and Smith (1997) proposed a number of developmental and maturational tasks normally undertaken during this adolescent period. These tasks included gaining independence, becoming more familiar and comfortable with their own body, building meaningful relationships, and identifying and developing a personal value system. Similarly, Havinghurst (1972) and Palmer et al. (2007) identified a number of developmental tasks faced during adolescence, including balancing the influence of peers and family, meeting societal expectations, and preparing for adult roles such as roles within the workplace. With the changes and challenges associated with this developmental period, Geldard and Geldard (1991) state that adolescents are often vulnerable to additional stressors. Therefore, with the addition of dealing with a life-threatening disease, it is not surprising that many adolescents with cancer feel a loss of self-esteem, control and independence, are afraid of being rejected by their peers and have issues relating to body image which can affect their sexual development (Abrams, Hazen, & Penson, 2007; Bellizzi et al., 2012; Gray et al., 1992; Madan-Swain & Brown, 1992). These can all result in reduced participation in social and physical activities (Abrams, Hazen, & Penson, 2007).

Erikson (1968) proposed that throughout the lifespan, people confront and aim to master distinct challenges associated with psychosocial stages. With regards to identity formation, Erikson described adolescence as a period when

young people are given the task of integrating their past experiences, their social context, and who they are into a stable identity. A stable identity will help to develop a sense of self-worth crucial to a successful transition to adulthood. Those who struggle to achieve identity formation may continue to experience confusion about future decisions and life choices. While this crisis becomes prominent in adolescence, attainment of previous stages such as autonomy and initiative is important for the development of a stable identity (Erikson, 1968).

Three of Erikson's psychosocial stages that are particularly relevant to the adolescent or young person with cancer include industry vs. inferiority, identity vs. role confusion and intimacy vs. isolation. The challenge of attaining industry as opposed to inferiority is where an individual strives for a sense of mastery over their environment. This could be impacted by a cancer diagnosis if the effects of treatment impact their memory or ability to complete tasks they had previously mastered, which can lead to reduced autonomy, and increased dependence on others (Abrams, Hazen, & Penson, 2007). Erikson's crisis of identity vs. role confusion is particularly pertinent to identity formation as the challenge involves the development of a sense of identity and forming a peer group. This stage can be challenged as adolescents with cancer can often feel isolated from their social groups. Finally the stage where individuals face intimacy or isolation is where the challenge is for individuals to develop the ability to form close, intimate relationships. While adolescents are only beginning this stage, what happens at this point might affect their young adult development, which is where this stage is more clearly placed. In addition, the development and interest in interpersonal and intimate relationships depends on having a positive sense of self and body image. Both of these are challenged during treatment due to the physical effects of cancer and feeling different from their peers (Abrams, Hazen, & Penson, 2007). Evan, Kaufman, Cook and Zelter (2006) suggest that as a result of low self-esteem and body image concerns commonly expressed by adolescents with cancer, young people with cancer often avoid intimate relationships.

Research on identity formation in adolescence has been influenced by work from both Erikson and Marcia. Marcia (1966) identified four statuses of identity formation. The first phase begins with identity diffusion, a stage where an individual has not considered or thought about their identity or future direction. The next status is identity foreclosure; those who remain at this level generally do

not consider alternative possibilities or viewpoints such as future career options or religious principles. Instead, they are more likely to take on unquestioned the values and expectations of important adults in their lives such as parents. Young people with this identity status may hold a single point of view and will strongly defend their viewpoint without considering other possibilities. Moratorium is a status where an individual considers and explores alternative viewpoints with regards to identity, but has made few commitments. The final stage, identity achievement, is characterised by an individual who has formed an identity based on values, beliefs and goals after an extensive period of exploring possible options (Marcia, 1966).

Although Erikson and Marcia have differing perspectives on the fine points of identity formation, there is a consensus that the development of identity is one of the key tasks of adolescence. Gavaghan and Roach (1987) worked with forty two adolescents with cancer and forty two matched controls without cancer. Participants were interviewed to identify factors relating to ego identity and were administered a sentence completion task related to ego identity developed by Marcia. Based on the results from the interview, Gavaghan and Roach found that healthy adolescents achieved higher ratings of identity status levels in areas of career, marriage and children. They also found that the healthy control achieved higher ego identity scores in comparison to those with cancer. They suggested that the adolescents with cancer were more likely to fall into the foreclosed identity status group than the healthy controls. A similar study by Madan-Swain and colleagues (2000) examined the differences in ego identity attainment for 52 adolescent cancer survivors and 42 healthy controls. Participants provided information on a self-report measure examining ego identity status. Madan-Swain et al. found that a greater number of cancer survivors were found in the foreclosed status when compared to the controls. This study also identified factors that were associated with the attainment of ego identity which included the type of cancer diagnosis, symptoms of post-traumatic stress disorder and higher levels of conflict within the family. Miller (1987) proposed a number of ways to help adolescents with cancer achieve development of their identity. Miller (1987) suggested giving genuine feedback, helping the adolescent to identify their own strengths and weaknesses, encouraging self-care and responsibility, and educating the young person on how they can manage their illness effectively.

An adolescent, like an adult, has the capacity to understand the meaning of their illness, including possible consequences. However, the adolescent may not have the cognitive maturity to fully understand or accept the demands and implications of the cancer diagnosis, which can overwhelm the adolescent's newly found independence. This reliance on parents for emotional support, advice, and even practical assistance such as being taken to hospital for treatment and checkups can be in conflict with the western culture's desire to gain autonomy in adolescence (Abrams, Hazen, & Penson, 2007). Therefore this conflict between wanting independence, yet requiring dependence can create problems within the adolescent-parent relationship; similarly, parents who become over protective of their child and limit their activities that can increase independence can also create a rift (Manne & Miller, 1998). A study conducted by Manne and Miller (1998) found that adolescents with cancer reported higher levels of conflict with their parents, in comparison to healthy adolescents.

Based on her research, Allen (1997) also found that young adolescents with a cancer diagnosis often face a dilemma, where they struggle to balance protecting their family from having to deal with the stress of the diagnosis, but also want the security and protectiveness of childhood. A study by Ellis and Leventhal (1993) found that in comparison to their parents, adolescents with cancer tend to minimise the seriousness of their illness. In this study 37% of adolescents believed their cancer to be highly serious, in contrast to 75% of parents. One proposed explanation for this difference is the perceived invulnerability some adolescents' feel, similar to the construct "it will never happen to me" that many young people express (Thomas, 2007). This sense of invulnerability typical of this phase might be challenged by illness (Bleyer & Barr, 2007). While there is limited literature about how adolescents sense of invulnerability is challenged by a cancer diagnosis, an Australian study by Moore and Rosenthal (1992) examined 189 adolescents' perceptions of their risk in five health related areas including developing AIDs, contracting an STI, having a serious car accident or developing lung or skin cancer. They found that in general, participants believed their risk of experiencing these negative health events were below average in comparison with their peers. This suggests that adolescents may perceive their likelihood of developing health related problems such as cancer as very unlikely, which could have implications for how they cope with their

diagnosis. For example, those who were not expecting a cancer diagnosis may be less likely to believe it or might find it more difficult to cope with the diagnosis.

In line with the research on identity formation and the adolescent with cancer, recent literature has examined the identity transition from an individual with cancer to a cancer survivor (Cantrell & Conte, 2009; Jones, Parker-Raley & Barczyk, 2011). Many cancer survivors find it difficult to return to their old lives, even though they desire this return normalcy. They struggle to regain who they used to be and some have to establish a new or adjusted identity. A study by Cantrell and Conte (2009) interviewed six young adult survivors of childhood cancer. A theme that emerged from these interviews included having to “reinvent the self”. This suggested that after completion of treatment, survivors faced a struggle between going back to their life before having cancer because they were no longer sick, but acknowledging they are not the same as who they were before their diagnosis.

Another goal during the adolescent period is to transition from being a teenager to being a young adult with more responsibility, to become prepared for adult roles, and to start thinking about future work. In a study by Palmer and colleagues (2007), six Australian adolescents who had experienced cancer were interviewed regarding what they believed to be unmet in terms of their social, psychological and physical needs during the course of their illness. An area of main concern expressed by the adolescents was fears around the future. Palmer et al. found that adolescents in their study believed that cancer treatment has a considerable impact on the adolescent’s ability to complete school and find and maintain a job. This fear may have led many participants in this study to feel uncertain about their future direction. This uncertainty is evident in a number of comments made by participants in the study, such as “I got totally lost after I had cancer. I was told I couldn’t do my job anymore, so I was just trying to think of what I was going to do with my life now.” (Palmer et al., 2007, p.132).

To further examine the adolescent cancer experience, Stegenga and Ward-Smith (2009) conducted a qualitative study with ten adolescents following a cancer diagnosis. This study identified six distinct themes relevant to this population; these include a loss of normalcy, a need for information, the importance of peers and how they reacted, getting used to the illness, being able to

give back, and family support. Each individual expressed how different they felt from their peers; this is particularly imperative to adolescence when one feels a need to be accepted by their peer group (Conger & Galambos, 1997). An interesting finding was that many of the adolescents expressed an altruistic desire to give back; some participants mentioned wanting to help others who were behind them on the cancer journey, while others were thinking about how their possible career pathways could contribute. For example, one participant discussed pursuing a career in broadcast journalism as a way to increase awareness about cancer.

### *Coping strategies*

With the challenges associated with both the developmental tasks of adolescence and dealing with the stressors associated with a cancer diagnosis, researchers have been interested in finding out how adolescents with cancer cope and adjust to their illness. Decker (2006) suggested that for an adolescent to adjust successfully to their experience of cancer, they have to “effectively manage their emotions and behaviour, interact with the social and non-social environment, and think in new ways in their attempt to alter or decrease sources of stress” (p.124). This is extremely important with regards to adolescents dealing with cancer, as effective coping can result in not only short term relief, but can also contribute to long-term social, cognitive and behavioural outcomes (Decker, 2006).

A literature review by Decker (2006) found that adolescents with cancer utilised a number of coping strategies for dealing with their illness. These can include problem focused, emotion focused and avoidant coping strategies. Problem focused coping strategies are aimed at seeking information, problem solving and actively doing something to change the situation creating the stress (Carver, Weintraub, & Scheier, 1986). Emotion based coping strategies are aimed at reducing the emotional distress associated with the stressor, rather than dealing with the actual stress. This can involve expressing emotions and seeking support from others (Band & Weiz, 1988). People are more likely to use problem focused coping strategies when they believe they can do something constructive to reduce the stressor; in contrast, emotion focused coping is more common when people

believe their stressor is something that has to be endured (Carver, Weintraub, & Scheier, 1986).

Avoidant styles of coping involve an individual using cognitions or behaviours that enable them to avoid thinking about the problem, or to avoid the problem in general. Some strategies of avoidant coping styles include denial, substance use, behavioural disengagement and the use of withdrawal (Decker, 2006; Turner-Sack, Menna, & Setchell, 2012). Individuals who utilise an avoidant coping style generally try to distract and distance themselves from their current stressors. However, Turner-Sack, Menna & Setchell (2012) posit that those who use avoidant coping strategies generally have higher levels of distress following a cancer diagnosis, including increased levels of depression and anxiety when compared to individuals who use less avoidant coping strategies. This suggests that those who are able to face their challenges directly are less likely to feel burdened by their illness and have higher levels of wellbeing. The implications of this finding for professionals include that they could encourage young people with cancer to consider alternative forms of coping, rather than an avoidant style. Decker (2006) suggested that adolescents who felt uncertainty regarding their illness were more likely to demonstrate an avoidant coping strategy. An important finding in this review was that a positive family environment was negatively related to an avoidant style of coping. This suggests a stable family environment may influence how a young person copes with the illness.

A qualitative study by Weekes and Kagan (1994) investigated coping strategies at different stages of the cancer diagnosis for 13 adolescents. These stages included three months before treatment was finished, at completion of treatment, three months following completion of treatment and six months following treatment. By using a semi-structured interview, Weekes and Kagan found that the differences in strategies reflected the distinct challenges each individual was facing at their stage in the journey. For example, prior to the completion of treatment, the adolescents used five main coping strategies; these included distracting themselves from the illness and treatment, keeping themselves busy, cognitive reframing, positive thinking and taking one day at a time. However, following completion of treatment, strategies used included negotiating control with parents, trying to reconnect with friends, blocking out negative experiences of their illness and focusing on how much their condition

had improved. These strategies were more likely to help the young person move forward.

According to Palmer et al. (2007), an adolescent's cancer journey is influenced by their current developmental stage. For example, while some adolescents feel prepared to cope with all the information regarding their illness and treatment, others felt overwhelmed and fearful when given too much information at once (Palmer et al., 2007). In order to work effectively with this group, professionals have to keep in mind the individual developmental level of the youth. Therefore it is important to acknowledge the difference between how an early adolescent such as a 13 year old might deal with these challenges in contrast to a late adolescent. For example, a study by Bull and Datar (1991) compared how 39 school aged children and adolescents who were in remission described their life stressors and coping strategies. This was investigated by administering the Children's Stress Inventory and a stress and coping measure specifically related to cancer. Findings of this study suggested that compared with school-age children, adolescents used more emotion-management and less problem-solving coping strategies when faced with cancer-related stressors. However, this was not the case when faced with general stressors that were not related to cancer. In addition, Decker's (2006) review of 12 studies examined differences in coping strategies used by young people with cancer based on their age. Generally, the studies suggested that the use of specific coping techniques such as distraction, cognitive restructuring, the use of social support and emotional regulation increased with age. Some reasons for these differences may include neurocognitive changes that occur in adolescence that result in the development of executive functions such as decision making and planning, organisation of ideas, abstract thinking and the ability to monitor one's own emotional responses. In addition, adolescents show evidence that they can selectively choose which piece of information they want to focus on, which could aid the use of distraction type techniques (Yurgelun-Todd, 2007). Yurgelun-Todd (2007) also suggests that cognitive changes in adolescence result in an "increased ability to read social and emotional cues and an increased appreciation and dependence on interpersonal relationships" (p.1).

A study by Turner-Sack, Menna and Satchell (2012) examined coping strategies and psychological distress of adolescent cancer survivors by working

with 31 individuals and asking them to fill out self-report measures of posttraumatic growth, coping strategies and symptoms. They found that adolescents who were younger at diagnosis were likely to report lower levels of psychological distress than those diagnosed at an older age. The authors suggested that perhaps this reflects the distress that older adolescents experience when thinking about their future and the ways in which their cancer may negatively affect their lives. They posited that younger adolescents may be less focused on their future. Turner-Sack, Menna and Satchell (2012) also suggest that perhaps younger adolescents are less likely to recall negative experiences of their illness due to their age, and that older adolescents are more aware of the seriousness of the illness. Older adolescents may have felt more impacted by missing out on school and the social isolation associated with their illness.

In a review by Compas, Jaser, Dunn & Rodriquez (2012), the authors found that coping strategies utilised by children and adolescents with chronic illnesses fit within a control based model of coping. This model can be divided into three styles of coping. The first is a primary control style (active coping) where efforts are made to reduce the source of stress or emotions associated with the illness, there is a secondary coping style (or accommodating coping), where the individual tries to adapt to the source of the stress and finally a passive coping style where efforts are made to minimise or avoid the stressor.

Studies have investigated the role of hopefulness as a way for adolescents to cope with cancer. Findings indicate that a higher level of hopefulness is related to a positive sense of wellbeing and commitment to treatment (Cantrell & Lupinacci, 2004). Hopefulness has been linked to increased psychological wellbeing and Abrams, Hazen and Penson (2007) suggest it may be because an adolescent who has positive expectations about their treatment and recovery is able to focus on specific hopes such as for health and to return to normalcy. They are then able to use these hopes as a way to adapt to their illness.

Juvakka and Kylma (2009) interviewed six adolescents between the ages of 16 and 21 who had experienced cancer. Two participants were currently receiving treatment, while the other four reported that they had recovered. The purpose of this qualitative study was to examine the importance of hope for these young people and also to identify factors that increase hopefulness. Factors

relating to increased hope for these young people included a positive attitude, humour and spirituality. Juvakka and Kylma (2009) suggested that humour in particular provides adolescents the ability and courage to escape from their situation and also gives them a way to make the situation more light hearted for their peers. The adolescents also discussed the link between hopefulness and the information they received during their diagnosis and commented how important it was to receive information at the right time and in a way that meant they were able to understand it. Abrams, Hazen and Penson (2006) suggest that “the adolescent who has positive expectations is able to focus on specific hopes as a way of adapting to their illness” (p. 627). Taking into account what adolescents with cancer cite as useful ways to cope with their illness can be extremely useful information for the services and agencies who continue to work with these individuals.

#### *Effect on relationships with peers*

Having cancer in adolescence can lead to emotional and physical isolation from peers, which can have a serious impact on social relationships. These social relationships play an extremely important role in the development of autonomy, identity formation and being able to identify personal values crucial to the transition from young adult to adulthood (Zebrack, 2011; Nichols, 1995). Many adolescents with cancer report that dependence on parents and health issues limits the social activities they are able to participate in (Haluska, Jessee, & Nagy, 2002; Zebrack, 2011). They often miss out on experiences that their friends are having, including dating, leaving home, going to university, getting married or having children (Haluska, Jessee, & Nagy, 2002; Zebrack, 2011). Relationships with peers were often affected by feelings of isolation and the belief that the adolescent with cancer was different from others (Manne & Miller, 1998). Weekes and Kagan (1994) found that 84% of adolescents with cancer stated that they viewed themselves as different from their peers and would not describe their lives as normal.

As mentioned above, there have been a number of studies examining the psychological wellbeing of adolescent cancer survivors in general. Over the past

twenty years, researchers have focused on examining the social outcomes of adolescent cancer survivors. Noll and colleagues conducted a series of studies (1990, 1991, 1993) that investigated relationships between adolescents and their healthy peers. They also examined perceptions and interactions during the period when the adolescent returned to school during the late stages of cancer treatment. Results from these studies by Noll (1991; 1993) indicated that while peers perceived those who had experienced cancer as being socially withdrawn and isolated upon reintegration to school, this did not affect the number of friends or popularity of the child with cancer. In contrast, a study by Nichols (1995) of 20 young adolescents with cancer found that this group had significantly smaller social networks than healthy adolescents.

Noll (1993) discussed findings from a longitudinal study of 19 adolescents who were not currently receiving treatment. Noll examined the psychosocial outcomes of these young people by incorporating teacher, peer and self perceptions of social standing, measures of friendships and popularity and self-reported levels of depression and loneliness. The ratings from the teachers in this two year study suggested that teachers perceived these students as lacking in leadership skills and social skills and being disengaged from their peers. These ratings may be related to the findings that some adolescents report feeling isolated from their peers on reintegration to school, as they feel they cannot participate in the same type of activities as their friends such as sports (Mattsson, Ringner, Ljungman, & von Essen, 2007). Some adolescents also reported that some physical effects of treatment, such as hair loss, affected their self confidence and decreased their desire to engage in social activities with peers (Manne & Miller, 1998).

Mattsson and colleagues (2007) interviewed adolescents two years after their cancer diagnosis and found that many reported a change in relationships with their peers during the illness and following treatment. This led them to feel isolated and many had lost touch with their friends. These beliefs were evident through statements such as “I don’t really have any great contact with really as many friends as I had before I became ill” and “They kind of just disappear. They kind of look away when you come” (p.1006). A young female suggested that perhaps her friends “can’t handle knowing about the cancer or something like that” (p.1006). However, when asked about some of the personal positive changes

that they had experienced as a result of having cancer, many discussed the positive effect on their perception of relationships. Many talked about a new appreciation and value for the important people in their lives and also being able to understand and have more empathy for those who are worse off (Mattsson et al., 2007).

Palmer and colleagues (2007) posit that changes to relationships may result from friends not knowing what to say to or how to react to news of a cancer diagnosis. Some adolescents with cancer note that their friends act uncomfortable around them or try to avoid them, which they find extremely confusing and distressing (Palmer, Mitchell, Thompson, & Sexton, 2007). As well as these behaviours from peers, adolescents with cancer often find it difficult to handle the attention and questions from their friends, regarding their illness. For example, in the study by Palmer et al (2007), one adolescent stated, “When people ask me how I am doing, I think ‘how do you think I am doing?’ but I say I am fine.” (p.49). This is a dilemma for peers supporting their friends with cancer. There is limited research providing information on what peers should do or what the young person with cancer would like them to do. However, it is likely that this is an important topic and research examining how to foster improved interactions, whether by helping the youth to ask for what they need, or educating the peers, is needed. Another theme identified in this study was the frustration of not being understood by peers, which led several adolescents to choose to withdraw from their friends. This is evident in one comment, “Most of my friends really couldn’t understand what I was going through and therefore the relationships didn’t feel satisfying.” (p.49).

With regards to friendships following completion of treatment, studies emphasise the importance of retaining friendships from before the cancer diagnosis (Mitchell et al., 2006; Woodgate, 2006). Ritchie (2001c) suggests that non cancer related friends can help provide a link to life prior to cancer and can be a useful tool for recovery.

While acknowledging the importance of reconnecting with peers the young people had before having cancer, Mitchell and colleagues (2006) also emphasised the benefits of forming and maintaining friendships with peers who have also experienced cancer. As they have been on a similar journey, they may

have a shared understanding of experiences and life following adolescent cancer. Wakefield and colleagues (2013) found that several adolescents reported the support received from others with cancer had been helpful, “My (CanTeen) friends were always there for me” (p.535). Following treatment, adolescent cancer survivors kept in contact via camps, the internet or other support groups (Wakefield et al., 2013).

When meeting others who have gone through cancer, an unfortunate outcome is that cancer survivors may lose a friend to cancer. This can lead to survivors’ guilt in some cases where individuals may feel guilty that they survived when others did not. This concept was discussed in a practical guidebook for those with cancer by Keene, Hobbie and Ruccione (2012) who provided a quote from a young woman, “When children I know die, I almost can’t look at their parents in the face. I know in my head that it’s not my fault, but it never feels like enough. I want to say I’m sorry I am here and your daughter is not” (p.39).

#### *Effect on the family and family relationships*

To deal with the demands of a cancer diagnosis, many adolescents turn to family for emotional support and practical help (Manne & Miller, 1998). While these can be a great deal of support to those suffering from cancer, due to the disruption to family and school life, the illness can also result in increased conflict within families (Chesler & Barbarian, 1987; Manne & Miller, 2012). In terms of possible effects and implications of this increased conflict, a study by Manne and Miller (2012) found that an adolescent’s conflict with their mother was correlated with increased levels of distress for a young person with cancer. Interestingly, conflict between siblings and friends did not predict psychological outcomes. This finding was consistent with other studies (e.g. Barrera, Chassin, & Rogosch, 1993) which also suggested that conflict with friends and siblings was not as correlated with psychological wellbeing in adolescents, in comparison with conflict with parents.

A review by Alderfer and colleagues (2000) examined studies and research of siblings of adolescents with cancer. They concluded that in general, the literature suggests that siblings do not typically have higher scores on measures of

depression, anxiety or behavioural problems when compared to healthy norms. However, a small number of studies found that siblings have an increased risk of experiencing negative emotions and cancer related post traumatic stress, particularly in the time immediately following diagnosis.

Studies examining the effect of having a sibling with cancer suggest that sibling relationships can be affected in a number of ways. This can include a change to the family structure and daily routines (Allen, 1997; Rollins, 1990; Woodgate, 2006). Studies have found that siblings of adolescents with cancer commonly identify themes such as “feelings of deprivation, displacement, injustice, anger, loneliness and vulnerability” (Whyte & Smith, 1997, p.140). This is consistent with findings by Sloper (2000) who found that siblings reported that they spent less time with parents and commonly felt neglected and lonely within their families. Rollins (1990) found that some problems may emerge if the sibling feels that their brother or sister is the focus of attention and this may result in feelings of neglect or resentment towards that sibling. The relationship between siblings may also become strained, if the healthy sibling has to take on additional work around the house to compensate for an ill sibling and absent parents (Manne & Miller, 1998). Disruption to these key relationships during this time can be extremely difficult, as it is when the adolescent most needs the emotional support from these people in their close social network. However, even though there are some negative effects on the sibling relationship, many adolescents with cancer report that the relationship and support from their siblings during their illness is invaluable (Whyte & Smith, 1997). In addition, Alderfer et al. (2000) suggested that there were positive outcomes that have been identified by siblings of those with cancer. These included increased responsibility, independence, and maturity of siblings; and increased empathy and compassion for others.

In addition to looking at the effect on siblings, studies have sought to examine the effect on parents who have a child with cancer. For example, Allen, Newman and Souhami (1997) conducted a study to investigate levels of anxiety and depression for the parents of 42 adolescents who had recently been diagnosed with cancer. Findings indicated that both mothers and fathers displayed significantly higher anxiety scores when compared to a control group, and 27% of mothers reported moderate to severe levels of depression following the diagnosis. In addition, a study by Norberg and Boman (2008) examined the self-reported

levels of depression, anxiety and symptoms consistent with post-traumatic stress disorder in parents of children with cancer. This study involved 266 mothers and 208 fathers who were asked to complete three questionnaires which included the Zung Self-Rating Depression Scale, the State-Trait Anxiety Inventory and the Impact of Events scale-revised. Results suggested that compared to norms from parents with healthy children, both mothers and fathers reported higher levels of both depression and anxiety. Norberg and Boman (2008) also suggested that parents of children with cancer have a vulnerability to develop symptoms of intrusion, avoidance and arousal, which are considered typical symptoms of PTSD. Also, this study found that parents whose children had recently been diagnosed generally displayed higher levels of distress than parents of longer term survivors. These are important findings, as parents who are struggling with their own issues may be unable to provide their child with the support they require during their illness. This suggests that it is imperative for professionals working with young people with cancer to consider how their parents are coping. Taking into account the parents' psychological wellbeing may provide more information on their ability to effectively support their child.

### *Avenues of support*

According to Kyngas et al. (2001), social support provides individuals a context in which to share their thoughts, experiences, and feelings and a way to cope with the distress they have related to their illness. Social support during a cancer diagnosis can also provide adolescents with feelings of acceptance, during a time when they can feel extremely isolated and different from their peers. Haluska and colleagues (2002) commented that "perceived social support is one of the most critical and effective factors in helping adolescents and adults cope with and adjust to life changes" (p. 1317).

Wakefield et al. (2013) conducted semi-structured interviews with 19 survivors of adolescent cancer, 21 mothers, 15 fathers, and 15 siblings of young people who had cancer. The purpose of this study was to examine the young adult cancer survivor and their families' perceptions of care and support following completion of treatment. This study found that all nineteen adolescents

interviewed commented that they felt an increased closeness and intimacy with family members after completion of treatment in contrast to before having cancer. Wakefield et al. (2013) also found that most young people that they interviewed reported that their parents were their primary source of support, but also emphasised the importance of support from their siblings. Adolescents most commonly identify their mothers as their primary support person during their illness (Woodgate, 2006; Ishibashi, 2001; Ritchie, 2001b). In a study conducted by Stegenga and Ward-Smith (2009) examining ten adolescents who had recently received a diagnosis of cancer, all ten emphasised the importance of family support. One participant in the study stated that her diagnosis had been an eye opener and had brought the family together. However, in this study the adolescents' believed the support they received from their family to be of secondary importance, while peer support was considered most important. This finding is consistent with the developmental desire of adolescents to develop independence from family and instead turn to other sources, such as friends, for support, but is in contrast with findings that suggest that mothers are a primary source of support during their illness as found by Woodgate (2006) and Ishibashi (2001). It is important to acknowledge that these findings may be influenced by a number of factors including how someone is asked, who is asked or the age of the person asked.

Woodgate (2006) worked with fifteen adolescents with cancer and using interviews, focus groups and participant observation examined what young people found to be most useful in getting through their cancer experience. In terms of peer support, Woodgate (2006) suggested that having one best friend that has known the adolescent prior to diagnosis and continues to treat their friend in the same way as before is more beneficial than having a large number of friends (Woodgate, 2006). In particular, peer support has a significant influence on the adolescent's ability to re-enter their social world following diagnosis and completion of treatment (Woodgate, 2006). Adolescents with cancer often refer to these best friends as their 'social shield', helping to maintain relationships with other peers, but can also act as a protector, shielding them from criticism from others and helping them when they feel self-conscious (Larouche & Chin-Peuckert, 2006).

Research has shown that while perceived as important, peers and family members are not always the first choice of support for adolescents with cancer. Palmer et al. (2005) found that some adolescents preferred support from teachers and other adults in their life, rather than their friends. They felt that adults were better able to relate to stress due to more life experiences.

Based on her quantitative study of 60 adolescents with cancer, Neville (1999) concluded that positive social relationships are associated with improved reports of quality of life and can provide an adolescent with an increased ability to cope with stress. In addition, having strong social support has been found to decrease psychological distress and uncertainty associated with adolescent cancer.

#### *Use of services and agencies*

As discussed earlier, young people with cancer form a distinct group who do not quite fit within a pediatric setting or an adult setting. This can create a number of challenges for services and agencies working with this population to consider. A Swedish study by Hedstrom, Skolin and von Essen (2004) examined which aspects of health care for adolescents with cancer were perceived as most important. This study examined perspectives of 23 adolescents currently in a pediatric cancer centre and 21 nurses through semi-structured interviews. Results indicated that there were a variety of areas which both adolescents and the nurses believed to be important. These categories included clinical competence of the staff, the adolescent having something to do and keeping amused, having continuity with developing relationships with the same staff, emotional support, flexibility in routines, the ambience of the wards, and family participation. Other areas that were considered important relate to providing the adolescent the ability to give input into their decisions and health care, and that nurses respect the fact that the adolescent is nearly an adult by providing them with accurate and honest information and give them space when they need it. This desire for independence and being actively involved in decision making regarding one's own body is consistent with the normal developmental tasks accomplished by adolescents during this time period (Whyte and Smith, 1997).

Both nurses and adolescents reported the need for correct and accurate information and a relationship with honest communication (Hedstrom, Skolin and von Essen, 2004). This finding has also been identified in other studies such as Dunsmore and Quine's (1995) study that examined informational needs of Australian young people between the age of 12 and 24 who had a cancer diagnosis. This study suggested that these adolescents were not receiving as much information as they wanted, with approximately two thirds of the participants wanting more information. The adolescents in this study reported wanting more information regarding how likely they were to have cancer again, long term effects, side effects and how their illness and treatment will affect their ability to have children in the future. Studies have shown that young people who receive open and honest information regarding their diagnosis and the prognosis of their illness are at a lower risk for depression and anxiety during this time, than those who do not (Last & van Veldhuizen, 1996).

Six Australian adolescents with cancer were interviewed by Palmer and colleagues (2007) regarding what they believed to be unmet in terms of their social, psychological and physical needs during the course of their illness. One participant was still receiving treatment for a non-Hodgkin's Lymphoma, while all other participants had completed treatment. Three broad areas of concern were identified, including the provision of information, the treatment process and what would happen following completion of treatment. Most participants were interested in issues relating to future fertility issues, and they all wanted more input into decision making processes. Participants wanted to be fully informed about treatment and wanted their peers at school to be educated about their illness and treatment by a health professional. All adolescents expressed ongoing concerns relating to the impact of their treatment, their future health concerns, and the chance of a reoccurrence. Most adolescents found there was minimal support available for psychological issues following treatment. This belief was expressed by one participant, who stated, "Everything is related to getting better but not past that point. . . . There is no one there to look after you after that." (Palmer et al., 2007, p. 131).

Another important aspect of a relationship between an adolescent with cancer and health care providers or agencies is that of trust and understanding. Having a relationship built on trust means that those working with the young

people are able to understand the adolescent's behaviour and actions from the young person's perspective (Ritchie, 2001a). An example described by Ritchie (2001a) is how some health care professionals struggle to understand how some adolescent patients are more concerned with side effects relating to treatment of cancer such as hair loss and weight gain, rather than the chance of remission. By recognising the developmental stage an adolescent is in and the importance of physical appearance during this period, professionals may gain a better understanding about a patient's fears relating to body image. This understanding emphasises that when an adolescent has cancer, they are forced into a position of dependence, at a time when gaining independence is so important (Drench, 1994).

A recent study by Wakefield, McLoone, Butow, Lenthen and Cohn (2013) examined the perceptions of support offered to Australian adolescents and their parents following completion of cancer treatment. Results of semi-structured interviews with 19 adolescents, 21 mothers and 15 fathers found that following treatment, both adolescents and their parents were reluctant to ask health professionals for help for fear that it would take time and resources away from those patients still receiving treatment. However, both youth and their parents still perceived the medical staff positively, in particular the oncologists and their GP's. Interestingly, perceptions of services with psychologists and social workers were mixed. Several families reported that accessing psychological services following treatment was difficult, and that those services without a cancer related focus were not appropriate. Mothers especially commented about how difficult it was to find local services with knowledge of psycho-oncology. One mother reported, "I don't think the people . . . had had a lot to do with cancer. I think seeing a psychologist up at the hospital probably would have been better." (Wakefield, McLoone, Butow, Lenthen, & Cohn, 2013, p.533).

Most families reported being involved with at least one charitable organisation following treatment; this included charities such as CanTeen, Camp Quality, Country Hope, Make a Wish and Redkite. However, the use of such services declined following completion of treatment due to the organisation being a reminder of the illness, feeling too old or feeling that the services would be better utilised by younger people still undergoing treatment (Wakefield, McLoone, Butow, Lenthen, & Cohn, 2013).

Research in this area has focused on the treatment and provision of services for adolescents with cancer. Wilkinson et al. (2001) suggested that areas of concern include age appropriate information for patients, involvement in decision making, being close to others going through the same experience and communication between adolescents and health professionals. Most recent research has suggested that there is a lack of adequate services and supports available to help adolescents to manage the combination of “cancer-related concerns and normal developmental challenges” (Palmer et al., 2007, p.128).

### *New Zealand context*

According to Williams (2006), in New Zealand approximately 160 young people between 15 and 24 years old are diagnosed with cancer each year. Similar to Australia, in New Zealand adolescents with cancer can be treated in an adult or paediatric ward (Mitchell et al., 2004). This fits with Palmer et al. (2007) assertion that adolescents with cancer make up a distinct group, who do not quite fit in paediatric care, or adult care services.

There have been limited studies conducted on psychosocial wellbeing of adolescents with cancer or how adolescents cope with cancer in a New Zealand context. However, a study completed by Wicks and Mitchell (2010) in New Zealand examined qualitative experiences of ten adolescents who had cancer. Across these interviews, important issues that were raised included treatment issues, information provision, hospital facilities, physical effects of treatment, emotional effects of treatment and the impact on developmental processes. A loss of control and benefit finding were also two subthemes identified in this study.

All but one of the participants in this study were able to spontaneously name at least one benefit that resulted from their experience of cancer; some of these perceived benefits included an improvement in relationships and personal changes such as an increase in motivation, confidence and maturity. This study also emphasised the negative impact of a feeling of a loss of control; the participants reported that this lack of control was greater in the medical domain rather than the personal or social domains. Wicks and Mitchell (2010) suggested ways in which a sense of control can be enhanced in individuals with cancer.

Some of these strategies included involving the adolescents in treatment making decisions, giving them age-appropriate information and by offering a range of options and demonstrating flexibility.

Walker, Signal, Russell, Smiler and Tuhiwai-Ruru (2008) examined qualitative experiences of the cancer journey as experienced by 44 Māori patients who ranged in age from their early 20s to late 70's. While most participants had experienced cancer within the past five years, some had experiences of cancer dating back 20 or 30 years. Looking at this issue within a cultural framework is important, because research suggests that in New Zealand, Māori are 18% more likely than non-Māori to receive a cancer diagnosis and also have a 93% higher chance of dying from cancer (Robson, Purdie & Cormack, 2006). Although this research was conducted on all age groups, it is likely relevant to adolescents and their whānau as well.

A major theme identified in the study was the need for a holistic method of healthcare and support, whereby the patients also receive emotional and spiritual support, as well as medical care. Examples provided included incorporating the use of “mirimiri (massage), kawakawa leaves, metallic healing, reiki, and reflexology” (Walker et al., 2008, p.31) into the healthcare system for those who wished to use it. Some participants also commented that specific Māori support groups for cancer patients, survivors and their whānau would have been extremely beneficial during their cancer journey. After interviewing Māori participants who had experienced cancer, Walker and colleagues identified a number of recommendations to the health system and to health care providers. Some suggestions included more co-ordination between delivery providers, more Māori staff, staff that had more understanding of what it means to be Māori and to be aware that as a group, Maori are extremely diverse and to offer counselling and support groups for whānau.

It is important to acknowledge that the New Zealand population is culturally diverse and that this may have particular implications for adolescents. For example, cultural issues which may be pertinent for this age group may include how the development of an identity might be impacted after leaving one's home country to migrate to New Zealand. A young person from a different cultural background may face a challenge of attempting to acknowledge and

integrate their previous cultural identity, into their current identity living in New Zealand. Furthermore, cultural understandings of illness may impact the way an individual comes to understand, perceive and process their illness.

As discussed in this chapter, previous literature in this area has examined the psychological and physical effects of having cancer in adolescence. In addition, research has examined coping strategies utilised by young people with cancer and has sought to find what young people believe was unmet during their illness and recovery in terms of support and need. While a number of studies have examined some of the psychological and psychosocial effects of having cancer in adolescence, there has been limited research conducted on this population within a New Zealand context. Therefore, this thesis has a particular focus on the impact of adolescent cancer on social relationships, coping strategies and social support within New Zealand. Reasons to focus on this context would be to examine if young people with cancer in New Zealand feel their needs are unmet in terms of the services, support groups and people they work with. In addition, there is limited research providing information on what peers should do or what the young person with cancer would like them to do during their cancer journey. However, it is likely that this is an important topic and research examining how to foster improved interactions, whether by helping the youth to ask for what they need, or educating the peers would be useful.

The aim of this study was to examine the impact of cancer and coping with cancer on young people, who had cancer between the age of 13 and 20 and who are currently between the ages of 16 and 24. In particular, qualitative interviews examined the following questions:

1. What impact did having cancer have on relationships with others including peers and family members?
2. Where did young people find support during their illness?
3. How did having cancer affect the developmental tasks of separation/individuation and identity formation?

4. What coping strategies did these young people use to adjust to their illness and treatment?
5. What would have been beneficial or helpful during their illness that they did not receive?

## *Chapter Two:*

### *Methodology*

#### *Participants*

Inclusion criteria for participants were that they had received a diagnosis of cancer between the ages of 13 and 20 and were currently between the ages of 16 and 24. Typically for the purpose of research regarding cancer and young people, most studies consider adolescent cancer to affect those between 15 and 19 (Barr, 1999); however, to widen the scope of potential participants in this study, those who had cancer at ages that fit slightly outside that range were also included. This age range was chosen as their experience of adolescent cancer was likely to be quite recent and easier to reflect on. To include a broad range of experiences, participants with any type of cancer diagnosis were eligible, and there were no inclusion or exclusion criteria based on treatment or prognosis.

A total of eight participants were recruited for this study. All participants identified as European and were currently aged between 17 and 24. Two participants were male, while six participants were female. The age at which they were diagnosed ranged from 13 to 20. There were a number of different cancer types identified, with Hodgkin's Lymphoma being the most common, which was the diagnosis of half of the participants. The treatment duration varied depending on the cancer type, the shortest duration for treatment was a single surgery while the longest treatment was approximately two and a half years. No participants currently had a diagnosis of cancer and they were all in remission.

#### *Advantages of Qualitative Research*

Burns and Grove (2008) highlight that qualitative research can be an extremely useful tool for the development and testing of new ideas or topics. This is particularly important in social science research, where it is rare that theories are one dimensional (Vishnevsky & Beanlands, 2004). Instead, qualitative research has the ability to encompass the complexity of human experience. Coyle

(2007) stated that when conducting qualitative research, the researcher has the ability to explore contextual factors such as relationships with partners and family, and issues relating to social class, gender, ethnicity and occupational status, in an attempt to fully understand what influence one's context has on attitudes, beliefs and behaviours. This type of exploratory research provides a setting where participants are able to discuss meanings that they see as affecting their life without restrictions from other research or researcher expectations (Coyle, 2007). This is important for this particular piece of research as it is likely that the experience of cancer and how it has impacted the young peoples' lives will be influenced by their social context including their family, their spiritual beliefs and cultural values.

Another benefit of qualitative research is the relationship between researcher and participant. The researcher needs to be able to work as a collaborator with the people they are working with, as equals. This relationship will hopefully encourage participants to openly and honestly share their experiences and understandings (Streubert-Speziale & Carpenter, 2003). This relationship is particularly important for this research because, with the nature of the topic and questions asked, participants are likely to share personal and honest accounts of their experience having cancer. Talking about potentially distressing and emotive topics can be difficult to do with someone they have just met, so the rapport and working relationship was imperative to ensure participants felt comfortable enough to discuss their stories.

Qualitative research analyses and interprets texts, rather than numerical data, to identify meaningful patterns across a particular area or phenomenon (Auerbach & Silverstein, 2003; Carter & Little, 2007). The purpose of qualitative research in a psychological field is to provide a rich, in depth source of knowledge and gain insight into an individual's understanding of their experience and context and how this relates to their feelings and behaviours. It is hoped that qualitative research will result in new information about a particular phenomenon or issue, and provide understanding and increased awareness into an individual's experience. This knowledge may then be used to support the development of a framework or tools relevant to the findings (Kearney, 2001). In contrast to quantitative research, researchers engaging in qualitative research do not usually

have a hypothesis in mind when starting research. Rather, they have a set of questions or topics to be explored (Carter & Little, 2007).

When considering how best to analyse the in-depth information gathered through qualitative research, it is useful to approach the research from a specific theory or epistemological background. Willig (2001) defines epistemology as a framework derived from philosophy, which considers how knowledge is understood and conceptualised. This framework encourages researchers to think about what and how they can learn what they need to know and to consider knowledge as a construct. There are a number of useful epistemological frameworks which can be used to underpin qualitative research. These can include objectivism which covers positivism and post-positivism, constructionism which covers symbolic interactionism, feminism, phenomenology and hermeneutic and subjectivism which includes post-modernism, structuralism and post-structuralism (Feast & Melles, 2010).

The approach used for this particular research project comes from the relativist social constructionism position that assumes that there is not one overarching truth or knowledge to be discovered; instead, there are multiple 'knowledges' that are influenced by value systems, beliefs, morals, cultural and background factors (Jankowski, Clark, & Ivey, 2000). This approach was used in this particular study because the experiences of cancer for these young people might be influenced by a number of contextual factors and qualitative research is one approach to exploring those experiences in further detail. By conducting qualitative research through a more naturalistic method, researchers are able to explore how particular social phenomena are meaningful to everyday life by understanding particular individual's experiences (Strubert-Speziale & Carpenter, 2003).

### *Limitations of Qualitative Research*

With the exception of clinical psychology, historically qualitative research has been overlooked within psychology for quantitative measures, which were arguably easier to validate and allowed the researcher to remain more objective.

This was due to researchers being able to measure, standardise and if needed, replicate observable behaviour or situations (Strubert-Speziale & Carpenter, 2003). The validity of qualitative measures are still questioned today, with some arguing that the use of a variety of methods in research as opposed to a single method may lead to a lack of reliability and rigour (Diefenbach, 2009; Forrester, 2010). While specific guides have been written by some of the authors of these methods with explicit rules on how to analyse data in a systematic manner, when these qualitative methods are not used systematically, results may be distorted or inaccurate.

Another potential limitation of qualitative research is the subjectivity of the researcher. Researchers aim to remain as objective and non-judgemental during both the data collection and data analysis part of the research process as they can be. However, Diefenbach (2009) states that it is unrealistic to think that the influence of human factors can be completely erased from the research. Even when trying to remain objective, it can become difficult when considering the level of attachment between the researcher and the research topic. Instead, it is advised that issues relating to subjectivity of the researcher can be minimised by being clear about assumptions, biases, the interests and aims of the research, right from the outset (Deifenbach, 2009).

### *The Researcher*

The success of qualitative research depends on the ability of the researcher to reflect on their own biases and interests and to consider how this may impact on their own thinking around their research topic. Reflecting on this, as a researcher I was able to consider how some of my personal experiences and value systems prompted an interest for me in this area and also how my experience affected my analysis of the findings and recommendations in this research.

Although I have always had an interest in health and health psychology in particular, my personal interest within this area emerged when I began volunteering for Camp Quality in 2012. Camp Quality is a non-profit organisation

that runs week long summer camps and mini winter camps for young people aged between 5-16 who have lived with cancer. In addition, they also invite siblings in that age range to attend for one summer camp. On these camps, these children have the opportunity to forget about their illness and instead focus on being a child and engaging in activities that they may have missed out on such as swimming, rockclimbing and archery. Since my time volunteering with Camp Quality, I have attended two summer camps and two winter camps.

In terms of my own biases and how that may influence my thinking around this area, I reflected on my initial reaction when I first met the children at Camp Quality. I have found that nearly all the children I have met through the camps have had a really positive and resilient attitude towards life and it was rare for them to ever say anything negative about their illness. While this may have been influenced by the context at which I spend time with these children, it may have impacted my expectations for the people I could be working with in this research. For example, I may have been expecting this similar positive perspective from the young people I interviewed, and may have been quite surprised if they had presented with a more negative attitude. This may have impacted the interview process if participants found it more difficult to talk about negative things if they thought that I as a researcher, was expecting, paying attention to, and prompting positive comments.

Furthermore, my interest in clinical psychology has allowed me to gain some knowledge on how people cope with difficulties such as illness and some of the theories underpinning these ideas. In order to minimize the effects of my expectations on the interviews, I constructed a semi structured interview guide that allowed the participants the flexibility to discuss issues and ideas they thought relevant. In addition, to minimise the effect of my own bias and interpretation in the analysis stage of this research, I followed a detailed process as outlined by Braun and Clark (2006) for completing qualitative research as closely as I could.

I also considered the influence I may have had on the interview process. I am an European female in my early 20's who has studied at university for the past six years. I was aware that potentially some of the participants may feel a power difference between our roles, my role as a researcher to their role as participants. To minimise this power differential, I tried to make the interview process as

comfortable as possible by engaging in casual conversation prior to the interview. Furthermore, another consideration was that as I was likely to be a similar age to some of my participants and from the same area, I also emphasised the point of confidentiality and that what was discussed in the interview would be completely anonymised and kept between us.

### *Ethical Considerations*

Ethics approval to conduct research with human participants was obtained from the University of Waikato's School of Psychology Ethical Review Committee. There were a number of ethical considerations relevant to this particular study. The first was that some of the subject matter discussed in the interviews may have been uncomfortable for some, as it involved talking about their experience of cancer. While some participants did bring up issues relating to death, fear, grief and loss, no participants felt too distressed to continue the interview at any time. Prior to the start of the interviews I emphasised that participants could decline to answer any question if they wished and could stop the interview at any time. However, no participants declined to answer any questions and no interviews were terminated.

Another important point to consider was potentially differing understandings and conceptualisations of death and dying that may exist between me and the participants. This is important to acknowledge as it is imperative for me as a researcher to be aware of the potential differences in viewpoints and to think prior to the interviews how to appropriately respond to these issues. To discuss ways to safely respond to these issues and as part of the ethical review process, cultural consultation was undertaken with Dr. Armon Tamatea. Some of the points discussed included the potential of cultural and spiritual explanations for cancer that might be discussed. For example, in the Maori culture there may be feelings of shame or guilt around a cancer diagnosis possibly due to things the family may have done in the past that has affected their wairua.

An important point that was raised was as a researcher, I need to be aware of and monitor my own reactions to what is said in the interviews and to be prepared for unexpected answers particularly around death and dying.

Over the course of meeting with participants, there were no evident cultural misunderstandings that arose. This may have been because I shared a cultural background with the participants, who all identified as European. However other differences such as religious differences may have existed, but did not come up in the interviews. Even though unfortunately no participants that came forward for the study identified as from another culture, reflecting on the process it was important to take into account how family, spiritual beliefs and cultural norms informs understandings of concepts such as grief and death.

### *Recruitment*

Participants were recruited for this study in a number of ways. Initially, I contacted the Waikato branch of CanTeen. CanTeen is a New Zealand organisation that offers support for young people living with cancer, or brothers and sisters of those who have had cancer and who are between the ages of 13 and 24. After meeting with the Waikato Regional Manager, CanTeen gave their support to the project and offered to help with the recruitment process. They agreed to send out recruitment flyers (Appendix A) with their monthly mail out to all members (patient and non-patient) of the Waikato/ Bay of Plenty CanTeen group. Flyers were also sent out to non-patient members of CanTeen in case they knew anyone who might be appropriate to pass on information about the study to, such as siblings or friends. I attended one of CanTeen's monthly regional council meetings where I gave a short presentation about my research. CanTeen also posted a brief Facebook post for the Waikato/Bay of Plenty group with contact information and a brief overview of the study. I also drafted a press release for submission in the Hamilton Press (Appendix D), a weekly community newspaper delivered to houses in the Hamilton area which was published in the paper. This press release also covered the overall purpose and aims of the research as well contact information. In addition, I placed posters around Wintec and the University of Waikato, placed an ad on my personal Facebook page and spoke to

the Communications Director of the New Zealand Cancer Society, who also posted an ad on their Facebook page.

### *Research Procedure*

After the distribution of flyers, the press release in the Hamilton Press and ads on Facebook, participants started to get in touch via email or phone. During the first contact, I gave more information on the study and answered any questions. For those who wanted more information on the study, a participant information sheet (Appendix B), which included the purpose of the study and had more information on participant rights in research was emailed out. At this time, I emailed out a copy of the question guide (Appendix C) which provided an overall template for what the interview would likely cover. If the participant was happy with moving forward, an appropriate time and venue was organised. The venue was decided at the discretion of the participant, and participants were given the choice of meeting at their home, somewhere in the university such as a room in the psychology department or library or another mutually agreed upon location such as a quiet café. When arranging interviews, all participants were informed that they could bring a support person during the interviews if they wished. Participants were also told they would receive a \$15 voucher as a token of appreciation for participating in the study.

Before each interview started, I spent at least five minutes talking to the participants about what they had been doing that day and engaging in general discussion to make the participants feel at ease. I gave the participant a copy of the participant guide and went through the purpose of the study, confidentiality, and what rights the participants have. Participants were informed that all interviews would be kept confidential unless it became apparent that there was risk to either themselves or to others.

At this stage, I informed participants' that the interview would be audio recorded, to be transcribed at a later time, and asked if they were comfortable with that. They were also told that after I had transcribed the interview, a copy would be emailed to the participant to look over. If they wished to correct any inaccurate

information or have any part of the interview omitted, they could email the edited version back to me within one month. If I did not receive a copy of the transcript back, I was to assume that the transcript was accurate. After reading through the participant information sheet, the participants were given an opportunity to ask any questions they might have. Participants were then provided a copy of the interview question guide to look over and were again asked if they had any final questions. If they felt comfortable to continue with the research, they were given a consent form to sign. They were also asked if they would like a copy of the summary of findings from the research; if they did they were asked to fill out address and email details.

The interview was semi-structured to gain more insight into the experiences of the participant's experience of cancer. This type of qualitative interviewing provides the researcher with a chance to find more information and probe about any interesting comments or issues that arise in the interview. It also helps the interviewer obtain an authentic account of the participant's experience in a flexible way (Seale, 1998). The structured nature of the interview helps guide the interview when participants have exhausted a particular topic and are ready to discuss a new topic. It also helped me keep interviewees on track, and discuss experiences relevant to this study. After completion of the interview, participants were given a \$15 voucher as appreciation for their time and contribution.

### *Analysis*

The transcripts were analysed using thematic analysis. The overall purpose of thematic analysis is to identify, analyse and report themes in qualitative studies and to provide a rich interpretation of the research topic (Braun & Clarke, 2006; Boyatzis, 1998). When conducting a thematic analysis, the researcher is aiming to identify overall themes within their data set. Braun and Clarke (2006) define a theme as something that has been identified as a patterned response, is consistent throughout the data set, and is relevant to the research question and something of importance to the data.

Advantages of thematic analysis include its flexibility, as it does not rely on any particular theoretical background, therefore it can be used across a number of theoretical frameworks. Thematic analysis can be useful for highlighting similarities and differences across data, can be used to summarise key features of a large amount of data and can provide insight into certain areas that may have been unexpected (Braun & Clark, 2006).

Braun & Clarke (2006) have suggested six steps for undertaking thematic analysis, but emphasise that the process is not linear. Instead, the analysis process can be considered recursive, where it may be necessary to move back and forth between the different steps. These were the steps I followed in the analysis of my data. The six steps of data analysis as detailed by Braun and Clarke (2006) are described below.

#### *Steps in data analysis*

1. Initially, my goal was to familiarise myself with the data. This was completed by re-reading transcripts and data. When I began analysing the data I read the transcripts in succession without taking any notes. When I read the transcripts for the second time and subsequent readings, I began to take a more active approach by starting to think about and noting down initial patterns and meanings in the data. This was prior to creating more formal codes.
2. The second stage of data analysis involved forming initial codes from the data. Codes were specific ideas associated with a piece of the data such as “distraction techniques”. By placing similar codes together, I started to organise them into meaningful groups. This was done by copying and pasting data directly from the transcripts into tables in Microsoft Word.
3. After being grouped together with similar coded data, the initial codes were then developed into potential themes.

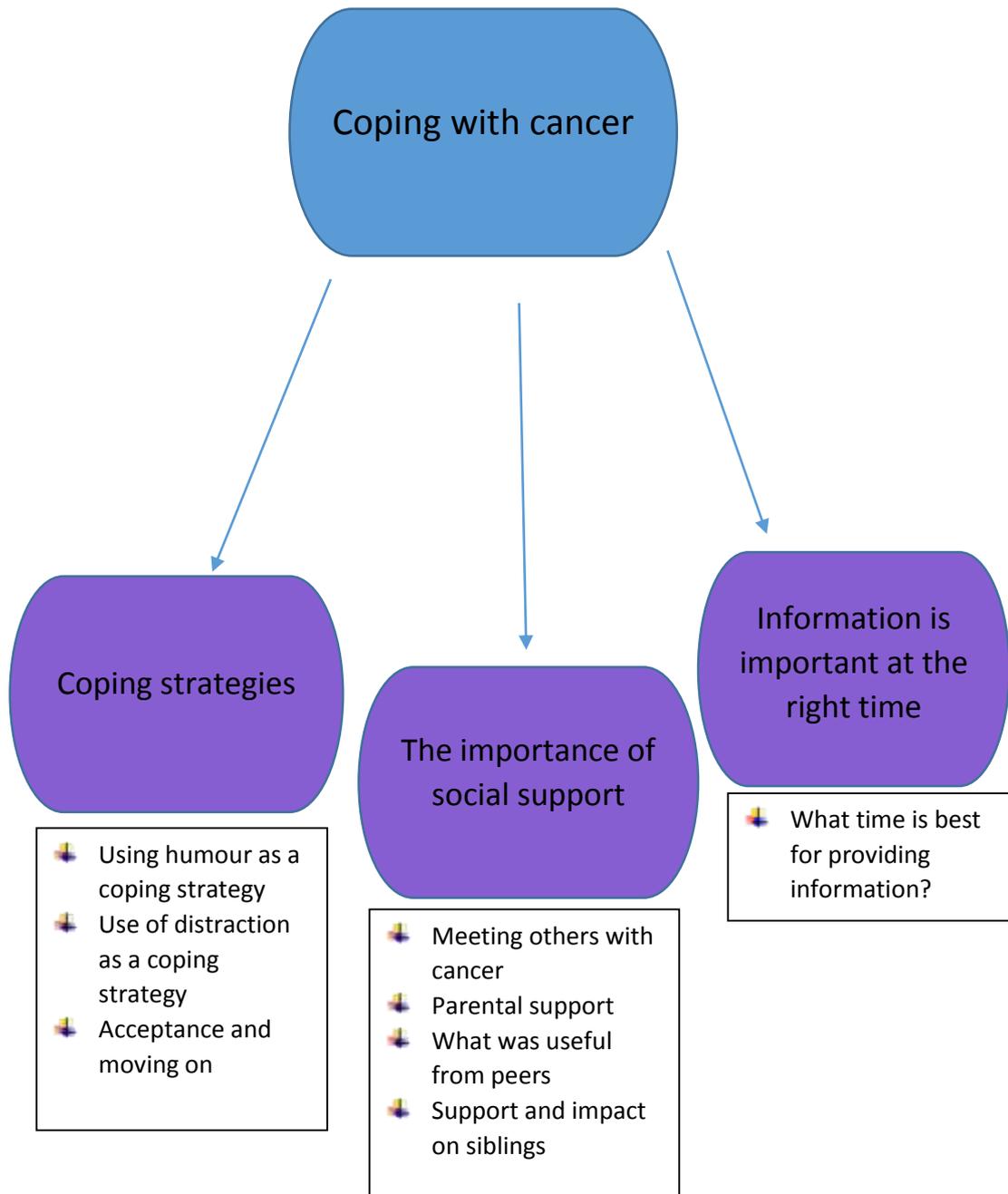
4. I reviewed the themes that were identified in phase three and refined them. During this stage, it became evident that the themes were quite broad and encompassed a number of smaller subthemes. As a result, the themes were split into several subthemes. It was at this stage that I considered if there was enough evidence to support each theme and subtheme. I also considered at this point whether the themes were consistent with the overall data set and the purpose of the research question by re-reading the literature review.
5. The fifth phase was where I defined and named my themes. Two overall topics that seemed to encapsulate the overall experiences of the participants were identified. These topics were coping with cancer and life will never be the same. In addition, I identified seven themes, which included, coping strategies, the importance of social support, obtaining illness related information, cancer as loss, cancer as a time of growth and development, relationships change and after the cancer is gone. During this stage it was important to identify what each theme was trying to capture overall, as well as what the subthemes were trying to capture. To do this I wrote a brief outline of each overall theme which was partially used in my findings sections of this thesis. I also tried to think about what each theme captures and also how it related to the other themes, as some of my themes overlapped. At this point, the data and the themes were discussed with my supervisor in order to get external input and feedback and reduce the chances that my expectations and implicit biases were shaping my interpretation of the results.
6. In the final stage I started to write up the analysis into a report. I took the seven completed themes and tried to provide a clear and coherent account of the themes and subthemes and how they relate to the data and the overall research questions. This report was adjusted to be used in my results section of this thesis.

## *Chapter Three:*

### *Summary of Findings*

During the analysis of the qualitative data, two topics that seemed to capture the overall experiences of the young people were identified. These topics were coping with cancer and secondly, that life will never be the same after cancer. These two overall topics were divided into subthemes to further describe the experiences of the young people interviewed. The first topic was divided further into themes examining different coping strategies, the importance of social support and that the provision of information is important for young people at the right time. The second topic was further divided into themes which were relationships change, cancer as loss and cancer as a time of personal growth and development. This chapter will provide a summary of the material in each theme, and selected examples from the interviews. While the themes are presented in this section as separate, many themes were overlapping and intertwined with one another.

*Coping with cancer*



*Figure 1.* Summary of themes and subthemes relevant to topic, 'coping with cancer'.

### *Coping strategies*

As presented pictorially in the figure above, all participants spoke extensively about ways in which they coped with their cancer diagnosis and treatment. They discussed a number of strategies they had used and a few commented on how well they believed they dealt with their illness. Subthemes identified within this theme included using humour as a coping strategy, the use of distraction as a coping strategy and accepting the illness and moving on.

#### *Using humour as a coping strategy*

Many participants described using humour as one way they dealt with their illness. Some participants still use humour when discussing what they went through, but said it was something that helped them particularly when they were going through treatment and trying to make sense of their situation.

*My sort of way of dealing with grief is to joke about it, I make some inappropriate jokes, I make jokes about cancer, you know. Its my way of dealing with things. I was using humour. (Tim)*

*I just turn to humour straight away. I was like Mum, I'm going to lose my hair right?, and she's like yes and she's like why is this funny and then I started laughing more and I was like cool I can get a rainbow clown wig, it's what I always wanted to do. I thought well if I'm going to lose my hair, might as well get a cool wig (Julie).*

Some participants also described how they used humour when talking to friends, in an effort to make the situation more lighthearted. Both Megan and Julie commented that using humour can have its limitations. As Julie acknowledged below, using humour was a not a strategy that would work forever.

*My close friends and I joke about it. I have to be careful who I do that with cause you know some people think it's in really poor taste, like how can you make jokes. But my friends, they get it. (Megan)*

*I think partially I used humour. I think humours a good way to cope with things in certain amounts, but you kind of can't just constantly be laughing about something, cause then it's not funny. (Julie)*

#### *The use of distraction as a coping strategy*

Participants often described that they were likely to try to distance themselves from their cancer and to avoid thinking about what they were going through. This could be through participating in activities that helped keep their mind off the illness or refocusing their thoughts on to different topics. For example, Belinda reported that reading helped to keep her mind off her diagnosis,

*Yeah I read a lot of books as well, but I think, it sounds stupid again but I would read books cause they take you to another place. (Belinda)*

Other examples as described by the participants are listed below.

*I feel that I distracted myself alot, I would not think about the cancer much. I'd spend all my time doing other things whether it was watching junky television, going out walking. Actually I went to the gym alot when I was having chemo, which is what they advise against, but all the time I'd go on the crosstrainer and it'd help pass the time (Liam).*

*After my treatment, I refocused myself. Instead of thinking am i going to die? I sort of thought let's plan a party, let's do something else. I wanted to keep my mind busy so I didn't think about that. Getting my mind around it was the main problem for me. Then after that week, I refocused on everything but the cancer. That was just my way to deal with it, by using distraction (Tim).*

Megan even commented that she refused to say the word cancer when telling her friends,

*I could not type the word cancer into my phone, I told them I have to start chemo and that was pretty much it. That was something I remember quite vividly, not using the word cancer. I was trying to distance myself from the word cancer, I'm like I'm not sick, I just have to have chemo (Megan).*

For some, it was a matter of protecting others such as family and friends that kept them from really thinking about what they were going through.

*It didn't really hit me until after I had finished my treatment because I was more worried about everyone else. Like, my mum, they told her first and when they took me into the office I just took one look at her and I was more concerned about her than what my result was (Susan).*

*Acceptance of the diagnosis and moving on.*

Many participants commented that what kept them going through their experience of cancer was to accept what was happening and to focus on things that could help.

*At first I was like, I was in shock, is this real? I still, I was in shock but I calmed down pretty fast, I cried for the first little bit and then after that I was ok. This is what's happening, cool let's move on (Julie).*

*I'm not consciously telling myself to live, I'm just getting up in the morning and getting on with my day. It was like ok, I'm sick and when you're sick you have to do what you have to, to get better. Like if you have a cough, you take cough pills or whatever you do for that sort of thing. So yeah you get on with it, you're like well I have no other choice so you just do it. If you don't focus on what's ahead of you, you get so down in the dumps and that doesn't help anyone (Laura).*

Some participants expressed that dealing with the cancer was not a choice that they actively made. Instead, they accepted that they could not change their situation.

*You just cope with it, you don't have the choice to go back to what you were (Amy).*

*You get used to it, not used to it, you can't change it, that's what it is now, you get used to it. It's not ideal, but it's necessary. You learn to live with it, I suppose that's the same with any disability, you learn to live with it (Laura).*

### *The importance of social support*

As summarised in Figure 1 above, many participants emphasised the importance of social support both during their illness and throughout their recovery. Subthemes that were identified included the impact of meeting others with cancer, and the support they received from their parents. While acknowledging the support they had received from their siblings, nearly all participants spoke about how their illness had negatively impacted their siblings, and they emphasised that their siblings also need support during this time too.

#### *Meeting others with cancer*

All participants discussed the impact of meeting others who had experienced cancer. Some described agencies such as Canteen as very useful in facilitating meetings with others who had been through a similar experience. There was consensus among participants that meeting others with cancer was very useful and helped connect them to others who could completely understand what they have been through. Participants such as Susan emphasised that agencies such as Canteen provide an environment where young people are able and encouraged to talk openly about their experience of cancer, which when out in the world can be considerably harder to talk about.

*You're surrounded in a world where people are so afraid to say anything about it at all and Canteen gives you that environment where everyone is open (Susan).*

As Amy and Megan describe below, meeting others who have been through a similar experience was really useful as they had a shared understanding that others did not have.

*Yeah, it totally helped me to be able to process it. I can say as much as I can about how I am feeling, but it takes another person to know that feeling, cause it's not just a feeling where you know where such and such happened. Whereas say I was talking to you and you were a cancer*

*patient, and I could say well you know what it feels like when they put the gas tube down your throat and blah, blah, blah and you could say yeah, that's horrible. They just know what you're going through at that moment, and it's so much easier. So it's nice to talk to people who know what you're going through (Amy).*

Many participants described not wanting to tell their peers too much about their illness, as they thought they would burden their friends with their distress or had reservations about how they would react. As a result, nearly all the participants identified having an outlet to express how they were feeling to someone who really understood what they were experiencing was extremely helpful. As Megan described below, meeting others also helped to normalise what the young people with cancer were going through which was really important for the young people who felt so different from most of their peers.

*I think the chance to talk to people who know what it's been like so I didn't wanna tell my friends everything I was going through because I didn't want to be a downer, I didn't want to, you know, make them uncomfortable, so they'd ask me how I was, I'd be like yeah, I'm fine, how are you? Whereas, you go to something with other people with cancer who have been through cancer and like I said, a lot of them had it a lot worse than me so that put that into perspective but it was really good to just sit down and they'd say like two or three days after chemo I'd just be puking my guts out, I thought I was fine and then bam, it would hit me. And I'd be like oh my god, me too! You could have these normal conversations, about this crazy stuff which helped you feel more normal (Megan).*

Furthermore, some participants such as Susan as discussed below emphasised the importance of finding a place where the idea of cancer and living with cancer was normalised. This was important as it meant they could have conversations that might otherwise have been uncomfortable or might have been avoided in other settings.

*It's a huge relief to be able to talk to someone who has been through it and has a really good idea of what you have been through. You're meeting someone and developing a friendship with someone who has some idea of what you're going through and what's happened. I just find in Canteen*

*we're all sort of just talking about well this happened and we had this treatment and this many blood transfusions, but out in the real world there's so many other people who feel they have to walk on egg shells about that topic. And you just want to yell at them, it's not taboo, it's fine, you can say the word, it's a word (Susan).*

Laura also described the ongoing frustration when people try to understand what living with cancer is like and commented that having someone to talk to who has lived through that experience themselves meant that can understand can really make a difference.

*You just get to end up in conversation that you can talk about what you're going through, and the other people can understand it because the most frustrating thing is trying to explain your feelings to someone who just doesn't know what you are going on about. And I think, well, no you don't know what it's like, you haven't gone through it yourself, you don't know how I'm feeling and I can't explain it to you. It's so amazingly frustrating, it's beyond frustration actually. It's you don't know what I feel (Laura).*

### *The importance of parental support*

A common theme that emerged from the interviews was how valuable the young people considered their parents' support to be throughout their illness. While most participants acknowledged that their peers often struggled to find ways to support them, their parents were a source of constant support. Belinda identified her mum as her biggest source of support, stating:

*It would have been my mum, umm, I don't know I guess something like this happens you realise that blood is thicker than water. Your family is always gonna be there. Umm, I think even more so during this you know, when other people were turning the other way, they were never gonna do that. Me and my mum were already best friends, real, real close but yeah we definitely got a lot closer (Belinda).*

Julie also spoke of how her illness had impacted her relationship with her mother, stating:

*It made mine and my mum's relationship stronger, because my mum was there near constantly (Julie).*

While some participants struggled to recall exact things that their parents did to help support them during their illness, they spoke of how even knowing that they were around if necessary was really valuable to them in terms of what they needed. Both male participants spoke about how useful they found the support they received from their parents but discussed how they found it difficult when their parents expressed distress at their illness. For example, Tim described how his father reacted during his illness, stating,

*There was plenty of support. My parents were always really good, though it annoyed me like my dad would cry every five minutes for a while there and so you know he'd have to go out of the room which really annoyed me. So I was like I'm not gonna die, you don't have to cry (Tim).*

In contrast to Tim's description of his father becoming upset throughout his illness, Liam provided an example where he found it beneficial that his father was able to remain strong and not appear to be upset and distressed by the situation.

*I feel that he was just more approachable than my mum, I could tell him things and he doesn't get shocked, he was just very easygoing, he didn't care. You know he cares, but he doesn't in the sense that he gets upset (Liam).*

Belinda acknowledged the impact of her cancer diagnosis on her mother. She described the helplessness her mother felt when she became sick, commenting,

*I think she was trying to, you know, be strong and you know, find out the information and be a parent but she was freaking out too. I think that parents are there to protect you and she couldn't do anything (Belinda).*

*Useful things their friends did to help them cope.*

While all participants reported that their illness had negatively impacted their relationships with their peers in some way, several participants described ways in which their friends had been able to help and provide support during that time. As Belinda and Liam described below, what participants found useful was for their friends to contact them to reassure them that they were being thought about, even if they were not seeing their friends as often as before. Participants emphasised that friends treating them as they had before also helped them throughout the course of their illness and recovery.

*I was at home and I didn't wanna go out anywhere but you could still talk to your friends. It was good. Even though you weren't seeing them, they still wanted to know how you were and yeah keep in touch. That's a big part too, just knowing that they're there and that they care (Belinda).*

*I don't know, like I had a few friends that were around and were supportive and like they'd always text you and ring and say hey are you alright, do you wanna catch up still and hang out? And that was cool, that's what you needed (Liam).*

Some participants commented that it was surprising who they became closer to when they had cancer. For example, Megan stated,

*It did really surprise who did come visit me. One of the girls, she was in my group of friends and she was on my soccer team but we weren't really close sort of thing, she was a friend and we'd eat lunch together but she came and visited me and like brought her whole flat and was like oh are you bored, do you want some company? I'll bring everyone to come visit you, like where are you? So we'd just hang out in the hospital with all these random people, telling jokes and stuff. It was really cool (Megan).*

*Impact of siblings*

Nearly all participants acknowledged the support they had received from their siblings. For example, Belinda described how her brother helped her just after she received her diagnosis.

*He was quite supportive, like at the start obviously I was chilling on the sofa a lot cause I didn't want to walk around so he'd go and get me a drink, or ask me if I wanted anything. That was his way of helping (Belinda).*

Many participants described the impact of their cancer on their siblings. Some expressed guilt that they felt they were the cause of their siblings' distress and often were frustrated that they could not do anything to ease or reduce the effect on the sibling. In some examples, siblings were required to mature quickly and had to take more responsibility for themselves, while their parents were busy looking after and supporting the young person with cancer.

Tim described the effect of his cancer on his sister,

*My sister got heaps of freedom because she was 15 when I got diagnosed and my family were with me and she had to stay here with family, second cousins and still went to school. So she got a lot of freedom around that time and then when I got home, she had to get reigned back in, which was a mission in itself (Tim).*

Tim also described how hard it was for his sister, having to basically live on her own at the age of fifteen, and still have to concentrate on daily life such as school and sports and having to care about their sick sibling. Tim commented that seeing the impact on his sister was really hard,

*It was tough seeing that and knowing that you're sort of the cause of that. You just can't do anything about it really (Tim).*

Julie commented that she felt her sister almost resented her for getting sick and that perhaps felt like she had an easier time than her during adolescence because she had cancer.

*She was really, really upset. It hit her very hard. She really went off the rails. I think she also, she resented the fact that I was the youngest and I got things slightly easier than what her and Josh had but then once I got*

*cancer I could do anything, not that I really did, but I could do anything and not get in trouble and so I think that kind of frustrated her (Julie).*

Several participants commented that they felt their siblings often did not feel that they could say how they were really feeling or talk about how their sibling's cancer was impacting them for fear that it might take the attention away from the sibling who was dealing with cancer. This was evident in both Liam's and Tim's account below.

*My brothers, I know they had a hard time, but they didn't really show much of a reaction. They thought that if they showed they were having a hard time, it might detract from me (Liam).*

*They can't bring attention to it because your sibling has cancer, and they think well you can't be rude and selfish (Tim).*

According to the participants, siblings struggle to find the balance between being there to support a sick family member while maintaining their daily life and dealing with the impact the illness is also having on them, without wanting to draw attention to their needs.

#### *Information about cancer is important at the right time*

##### *Information is powerful at the right time*

Getting information about their illness was something most participants described as important and an issue that they discussed in detail. Gaining information at the right time was described by participants as crucial to understanding their illness and also to help the young person to deal with what they were going through. As detailed in the statements below, the right time to receive information depended entirely on the individual involved. However, Megan, Tim and Belinda all described that receiving information in the early stages of their diagnosis was not a good time, as they were still trying to come to terms with what they had been told. They also felt that being given that information at that point was overwhelming.

*I'm not sure when that happened but you know he was trying to explain, he was explaining all these facts and information, and I'm like I'm not really thinking about, I'm still processing what's happening (Megan).*

*At the start I probably didn't know very much. I think the focus at the time was on to get rid of the cancer as soon as we can. But I mean you don't really have an understanding of why it's so serious, why are we trying to get rid of it so quickly? The medical staff are the experts, so you roll with it (Belinda).*

Tim later commented that there came a time in treatment when he did feel ready to learn more about his illness and what he was going through and at the point wanted to find out more.

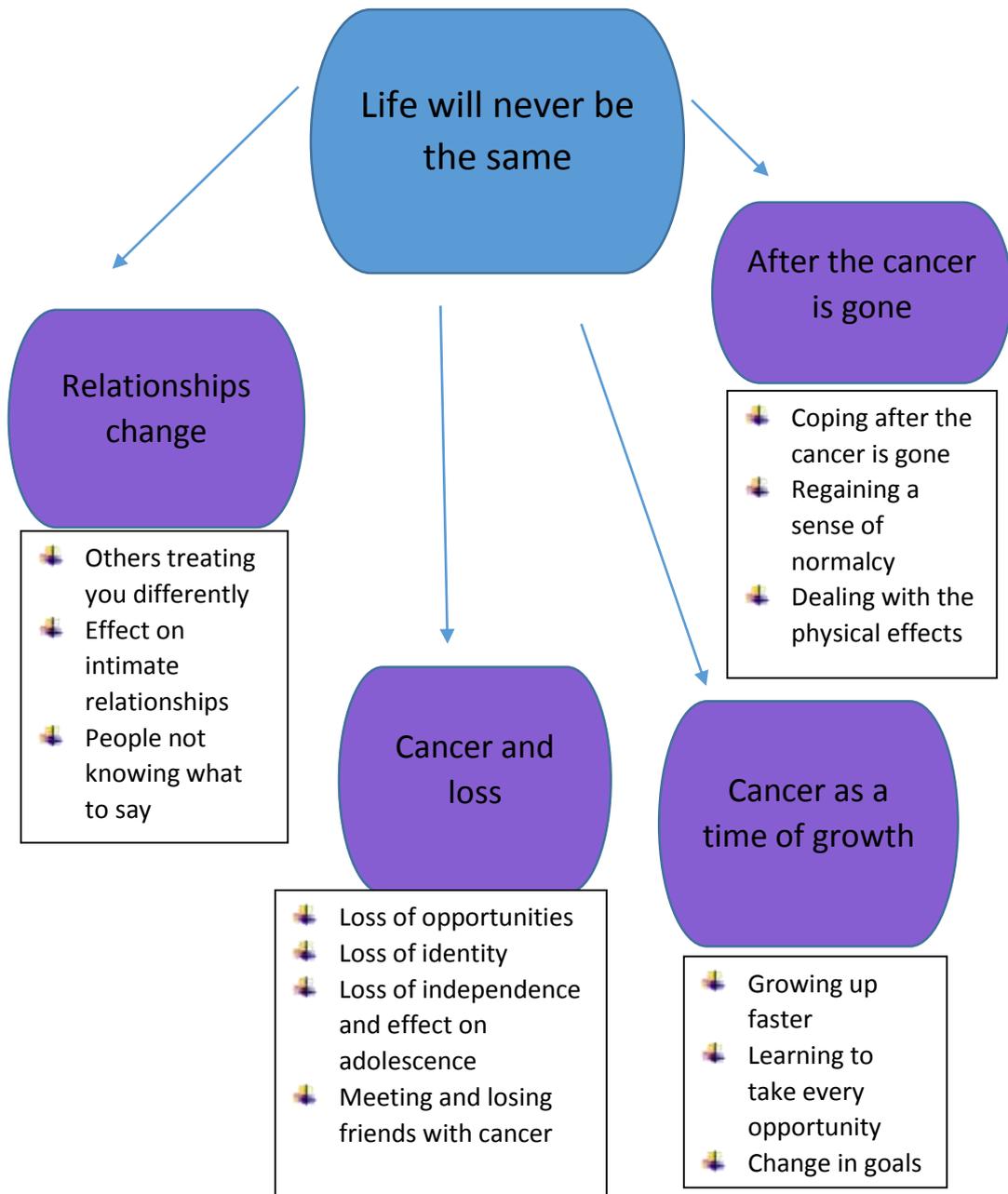
*At the time I got diagnosed, no information was good information. It's good because then you're not getting told oh you are going to die or this going to happen or what's going to happen. They weren't telling me anything and that was ok. By the time it was up to chemo and radiation, I was starting to get power from the information. Whereas, when I was going through my surgeries I was like I don't want to know about it (Tim).*

Three participants discussed who they felt was best to be provided with illness related information and Julie reflected on a personal experience where she had been left out of a meeting about her illness and had received minimal information.

*The day after I was diagnosed everyone went into this meeting room but I wasn't allowed to leave my bed, but I would have rather they all came into my room rather than leaving me there (Julie).*

Many participants expressed that they were comfortable with their parents being told more information than they were about their illness. That was particularly true in the time immediately following their diagnosis. However, they felt that as time progressed they wanted more information when they felt they were more able to deal with it.

*Life will never be the same*



*Figure 2.* Summary of themes and subthemes relevant to topic, 'life will never be the same after cancer'

As summarised in the figure above, participants expressed numerous ways in which they felt their lives had been changed by having cancer, and most accepted that their lives would never return to how they were before. Themes that

emerged from the interviews were life after the cancer is gone, cancer and loss, relationships change and cancer as a time of growth and development.

### *After the cancer is gone*

#### *Importance of continuing to cope after the cancer is gone*

Amy emphasised that while many people believe that the time a young person actually has cancer would be the most challenging time, in fact the consequences and effects of the illness continue well beyond the period of the illness itself.

*It's just the grieving process that you have to go through. Its hell, that's why I say the cancer itself is not the hard part, it's getting out the other side and still having to live with it (Amy).*

Some participants spoke about the differences between the period when they had cancer and the time following the completion of treatment. They reported that during their illness they were so focused on getting better that it was not until after the cancer treatment was finished that they were actually able to process what they had been through and think about how it would affect the next stage of their lives. Some participants, such as Laura, proposed that this can actually be quite different from other people's perspectives who perhaps believe that once the cancer is gone, the person should be ready to move on.

*There's so many people who think oh cancer's so hard and you're so brave going through it and I'm just like well, I didn't have a choice. It's not like I could say nah I don't want this sorry. But then they'd think well you're through treatment, and yeah I'm through that but I'm not done. I've still got, even after you finish treatment you still have to wait five years until you are cleared. And in my own experience the cancer part was the easy part, I mean living with it now, I'd rather go back to having the chemo every day.*

*After treatment was finished I went into a huge deep depression, and I got quite suicidal and things like that. It's taken very lightly I think, they think*

*oh well you get sick, you get medicine, and you get better. But it's not just as easy as saying, ok I'm sick, I'm gonna take medicine and I'll be better. Some people are like that and they just get on with it, but it's still with it, it got me down quite a bit (Laura).*

Some participants did not really have a chance to think about what having cancer meant until after they had been living with the illness for a considerable amount of time.

*I probably didn't cope with having cancer well at the start, it took a long time to get through it and get over it (Belinda).*

The time needed to process having cancer was also evident in a number of other participants' responses. For example, Susan commented that it was not until the end of her treatment that she really started to process what she was going through,

*I couldn't really handle it. It was sort of the end of my treatment that it started really hitting me, and by the time I was in fifth form I had a massive mental breakdown at school (Susan).*

This was similar to Julie's experience, where reflecting upon how she coped with having cancer, she stated,

*I don't think it had fully sunk in, it didn't sink in for a very long time, like I'm talking like at least a year until I kind of was like shit I actually have cancer (Julie)*

### *Regaining some sense of normalcy*

Many participants talked about their desire to regain some sense of normalcy. They acknowledged that having a cancer diagnosis would undoubtedly change their lives and they accepted they could never go back to how they were before. However, some participants commented that something that helped them was to think about how not everything in their life had changed, that some people

would still treat them the same and they would be able to do what they could before.

*My sister kept it real, and at the time my parents were really upset and she helped and came in and talked to me normally and gave me shit as sisters do. One of her gifts to me at Christmas was a black shirt which has a picture of a skull on it and it says your results came back and its not a tumour and it had a scan and inside it had like a poo. And all of her friends when she saw it and said I'm going to get this, no no, insensitive, and she was like nah I'm getting it. And I loved it (Tim).*

*The sobby, like oh you poor thing, I know how it feels, you must be upset annoyed me. We just want to talk about normal things not like, how bad their cancer is and how long they have to live (Liam).*

*Well when I say normal, what is normal? Umm, I guess you want to be how you were before but that's, I know now that that's never gonna happen. Umm, like I physically am pretty much back there except for a little scar, but mentally you know it's always, it's gonna change you forever (Belinda).*

*The day I found out and I was still in my pyjamas and I said to mum I'm going to go have a shower. That was my, you know, calming, processing it stage, have a shower and just be normal (Megan).*

Participants commented that they found returning to things that were familiar and they had done before to be a useful way of dealing with the illness.

*And coming home after chemo I was just like blah and so I didn't really, so I had my studies which was, I felt like I was accomplishing something and doing, that was normal. That was the little pool of normal. I tried to hold onto the normal and not well, obviously I did worry. I tried just not to worry (Megan).*

Wanting to return to how life was before having cancer was evident across participants' accounts, particularly when they were in the remission stage of their treatment. As Julie described below, when she was reintegrating back to school and back into her peer group, what she actually wanted and what would have

helped ease the transition was to be treated just as she had been before she had cancer.

*I had this one friend who I'm still friends with now and she visited me in hospital when I was at Waikato and so did a few others. And she just, she never changed how she treated me. Like everyone else wrapped me in cotton wool and wouldn't, she just continued saying you're still Julie. Nothing like had actually changed except the only difference was that I had chemo in my blood (Julie).*

#### *Dealing with the physical effects of the illness*

Many of the participants identified and discussed the physical effects from their cancer and their treatment for cancer. Most emphasised that cancer has had a considerable impact on their health and their ability to engage in certain activities. As described by the participants in more detail below, their experience of cancer did result in a number of physical effects ranging from eye problems to mobility issues or learning problems as a result of chemotherapy. This emphasised the variation in possible physical effects for people with cancer and the possible psychological impacts on those effects.

*Well because of the cancer, I don't play sports just because I'm not disabled, but there's no co-ordination between my head and my legs so I can't run. So that does limit me from a lot of activities, I can't exercise or anything. And it totally screwed up my eyesight, like on my optic nerve. So that was I think the word was irreparably, it's not gonna come back right. Cause I have double vision now (Laura).*

*Even now there's certain things I can't go and do, I still have balance problems, I can't walk properly, I still have the eye problems. There are even in job hunting, there are jobs I can't do, I can't be on my feet for long so I need desk job, because I need to sit down, not because I'm lazy it literally hurts me to be upright and standing for a long period of time (Amy).*

*So that can make it pretty interesting and then I have a learning disability because of treatment, and it kind of it can sometimes present as like dyslexia and so I'll go to say a sentence and it will be completely out of order and it makes no sense, and or I'll go to say a word and a different word will come out of my mouth, and that can get awkward if people aren't used to that happening and then they laugh and I'll feel worse (Julie).*

*I'm really slow, I can't really run very fast just because of some things with the cancer and tightened up ligaments or whatever and so yeah. So I can't really run (Tim).*

Several participants discussed how they felt extremely self-conscious during their treatment and because of the obvious physical scars cancer has left. This was evident in both Tim's and Belinda's account.

*It was a bit of everything that made me self-conscious. Obviously it was new for me too, so I didn't like it myself and as much as Mum would say you know it's a war wound, it shows that you've survived. You should be proud of it, you should be wanting people to see it. It didn't help at the start, I was like what are you on about mum? And I guess people looking and like that doesn't make you feel any better when people are just staring at it (Belinda).*

*I was still growing my hair out, and this is as thick as its going to get so at the time it was two or three strands like Homer Simpson. I was feeling awesome, and I had dropped down to, my starting weight at the beginning of treatment was 55 and I dropped down to 51.4 which isn't a big drop, but the fact that I was growing as well, I had started to look quite gaunt as well and pale because of my blood. So, I wasn't amazing, i felt self-conscious about that and I was wearing a beanie you know to hide my hair and that sort of put that off (Tim).*

As mentioned in Belinda's account above and as discussed earlier, further impacts were caused by these physical scars as people were more likely to stare at

the scars than ask questions which did cause some participants frustration and annoyance.

### *Relationships change*

As seen in Figure 2 another important issue that was raised by the participants was the impact having cancer had on their relationships. For some participants, their illness brought them closer to certain people. In some cases they spoke of being surprised who it actually made them closer too. However, many participants discussed how many friendships ended as they felt their friends simply did not know how to cope with what they were going through and found it easier to end the friendship. Nearly all the participants also discussed how cancer changed how people treated them.

### *Others treating you differently*

A number of participants commented that having a cancer diagnosis meant that they were no longer expected to perform at or reach the same standards as others or what had previously been expected of them. Participants expressed frustration that they were not given the same expectations, particularly when they were recovering from their illness and wanting to regain some sense of normalcy. One example provided by Tim was that his father now limits what he can do physically, and even though he feels he can do it, his father is reluctant to allow Tim to participate in activities that he had done before.

*My dad's the worst offender in some respects. He's like, it's heavy lifting; you can't do it and I'm like wait, I'm still able to do lifting, just not as heavy, but he's like nah you can't do this and I'm like why? So he's a main offender of that (Tim).*

Furthermore, Julie commented that her father once told her that would have encouraged her to try harder at school to achieve more academically, but because of the cancer did not end up pushing her as hard.

*I remember my dad saying once after I passed level one or two I don't know, I passed it but I didn't get exactly amazing grades cause I was pretty sick and I had a learning difficulty and I remember him saying, if you didn't have a learning difficulty and you didn't have cancer, maybe we would have pushed you a bit more (Julie).*

These lowered expectations also seemed to extend to other significant people in the participants' lives, such as teachers. Tim described how other people did tend to use his cancer as an excuse for lower standards for schoolwork.

*Teachers didn't really give me the standards they gave the rest of the boys, which at the start was really good as it was what I needed but then I was back at school full time, ready to do the same as everyone else but they didn't do that, which was hard and that's sort of starting to go away but it's still there (Tim).*

Participants described being perceived as vulnerable and weak and someone who needed to be protected from the world. While this did lead to some positive outcomes as detailed by Julie below, for others this was frustrating and kept them from regaining that sense of a normal life they desired. Some participants commented that there was a stigma against those who did say anything negative towards them and for Julie this meant she no longer was bullied at school.

*One of the good things about getting cancer was that it stopped me being bullied because I was severely bullied all through school and then once I got cancer they're like, I had a few things but most the time if they said anything and or did anything, they'd be all these other people who'd be so angry with them, like straight away leap to my defence (Julie).*

Others such as Tim and Laura expressed frustration at how people seemed to make allowances for them because of their cancer or seemed to treat them more delicately than they felt they needed.

*When I went back to school they did build this whole thing, you can't mock the cancer kid. So as I got stronger and I was able to join in and be there the whole day like we'd play handball, and they'd be like nah nah you're not out and I'd say well I just got out obviously and I'm cool with that. But*

*I'd have to walk out, otherwise they'd keep me in 'til whenever. And so it was more like he's the cancer kid, you can't be mean to him, you can't do this to him, you can't do whatever to him (Tim).*

*Some people just treat me differently now and I tend not to tell them because of that. They'll be like ooh she's had cancer, maybe we should treat her delicately. And I'm like no, don't treat me delicately (Laura).*

Participants such as Laura emphasised that people would often assume that a cancer diagnosis meant you could not help yourself. As a result there would treat them as helpless, which was a challenge for the young people who were craving their own independence.

*I hated it. Mainly because I was in a wheelchair and people will be like "oh I'll get it for you, I'll go get it" if I ever needed anything and I would say "no you won't go and get it, I will get it". I just got so sick of people trying to do everything for me, because I wasn't actually disabled. It was obviously a bit harder for me to do it, but I could do it. I kept saying I'm not going to let you do it for me. I don't know if that was just a me thing, but I was very stubborn in that sense. I just wouldn't let people do things for me. Um unless it needed to be done. I was like "no, I'm doing it!" (Laura).*

### *Effect on intimate relationships*

Many participants described the impact of their illness on the development of intimate relationships. For Amy, one challenge to this developmental process was that having cancer significantly impacted what she was able to do with her boyfriend as detailed below.

*They say you're not supposed to swap bodily fluids when you're on chemo, for good reason, so we couldn't even kiss, not that it stopped us. So my portocath was in and made even hugging hurt, so I was like a fragile doll and he was like where are your parts, where do you have little things that I'm not allowed to touch. It did make things a lot harder and of course*

*because I didn't have the stamina, I got tired very easily and so whatever we did together, had to be where we were relaxed. We couldn't do anything physical. It did end up ending the relationship because I felt like a burden, that he deserved better than this. I couldn't do anything (Amy).*

#### *People not knowing what to say*

A common theme that emerged from the interviews was that many friendships did not last, simply because their peers were unable to find ways to support their friend going through cancer. Participants described their friends not knowing what to say to them and not knowing how to act. Many participants commented that cancer was a taboo subject that many people did not feel comfortable enough to discuss. For many participants this was difficult as it was a topic they would rather have talked about than left unspoken. Both Tim and Belinda described incidents where they wished people would have asked them about their visible physical effects of cancer, rather than staring and not saying a word.

*I think at first people were being quite nice, but then that sort of changed. Umm, like they sort of stopped talking to you cause they just don't know what to say and then sometimes it was better that they didn't say anything. Cause when they did say something, it wasn't very nice (Belinda).*

*The thing was what really annoyed me, was when I used to wear the eye patch 24/7 and I'd be walking through town and doing whatever, and I'd have an eye patch on which is pretty interesting and then they'd stare, but they'd never ask you which started to annoy me. If they asked, I'd be happy to talk about it and myself (Tim).*

*Sometimes it comes up, I don't know how probably they see my scar. But you see some people looking at it and then some people ask, but more people just look at it and don't want to say anything which is probably more annoying than them just asking what's that from?(Belinda).*

Participants described friends not knowing how to deal with the effects of their illness. Julie recalled a time when her friend wanted to help support her through the loss of a friend but did not have the skills or ability to provide support.

*I know I remember being in high school and another one of my friends had just passed away and I remember sitting in my best friend's house and I just started crying and she just did not know what she should do, she was just like wow and then even now when I lose someone, it makes the others feel so much worse, one of my best friends is like I don't really know what to say, I don't know how to help. I want to but I don't know how (Julie).*

In the interview Liam reflected that he had lost a number of friends as they found it easier to leave him alone than feel uncomfortable not knowing how to react around him. This was also evident in a number of participants' accounts such as Laura who described the loss of friends who did not know how to respond appropriately.

*A lot of people distanced themselves, and since they didn't know what to say they wouldn't talk to you and would be out doing everything they wanted to do so why would they wanna come and see you who's stuck at home. And that was probably, that would have been for a good three months that people stopped talking to me (Liam).*

*Honestly a lot of people don't know how to deal with it, suddenly seeing a person who was so lively and active, like I was a dancer and happy. But just seeing that and then seeing me, not decompose, just draw into myself, and then the hair went, and you get this really sick look about you coz I lost so much weight and obviously I was dying, they just didn't know how to cope with it and I did end up losing quite a few friends. I presume it was due to them not knowing what to do and they didn't really want to face the fact that their friend was dying (Laura).*

Amy also commented that because she knew her friends were unlikely to be able to cope with what she was going through, she was reluctant to talk to them

about it. As their peers were not able to understand what they were experiencing, participants described this as a barrier to talking with peers about the illness

*I lost a lot of my friends, so I didn't get a lot of support from them. Obviously they didn't know what to do, they didn't know what I was going through, I didn't tell them a lot for that reason, that they wouldn't understand it (Amy).*

Similarly, Amy commented that she was aware that some of her friends might be uncomfortable talking about her cancer. However, she wished that they would have told her rather than just distancing themselves.

*I mean I'm ok with them being uncomfortable about it, all they had to do was ask are you alright, I was ok with not talking about it, it was almost as though they expected me to talk about it or something like that, and I get if you don't want to talk about it, we don't have to talk about it (Amy).*

Some participants acknowledged that not all their friends were emotionally equipped to deal with a friend with cancer. As a result, participants such as Julie described how important it was to be able to identify who they could talk to about their illness and who out of their peer group was unable to deal with the illness.

*I think it's just, you end up learning which friends you can talk to about which part. Cause some of them, they want to help, they really, really want to, they just don't know how to deal with it (Julie).*

### *Cancer as loss*

Many participants conceptualised their experience of cancer as a time of loss. This included a loss of opportunities and a loss of identity, grieving who they could have become, had they not had cancer. Some participants also expressed survivors guilt after meeting others with cancer who later passed away. In addition, participants described a loss of their independence.

### *Loss of opportunities*

Dealing with the effects of cancer and treatment was a common theme that was evident in several interviews. For example, Laura and Susan below discussed how their illness had impacted on their fertility and the resulting loss of their chance to have children.

*For one thing I can't have kids anymore, so that's one major thing. I mean, it's actually quite common for a lot of cancer survivors so, obviously the females. Yeah, it's not a matter of give it a couple of months, it'll go away and it'll get better. It's totally, that's it for me (Laura).*

*It has impacted on my future, cause with my treatment, there's a chance it has made me infertile. And there's a chance, that if I ever am able to have kids that they're going to get cancer as well and I worry about that everyday (Susan).*

As mentioned earlier, the loss of friends during their illness had implications for the young people and as a result many participants believed that they ended up missing out on social experiences with their peers. Some commented that this was perhaps due to their friends' inability to cope with the illness itself, or a preconception that their friend with cancer would not be able to participate in activities that required excessive energy. Many participants described feelings of social exclusion during and following their illness. For example Amy recalled an incident where her friends had a party that she was not invited to or even told about.

*Whereas most of them were like oh well, we know she can't come so there's no point in asking her, which really hurt me. I knew I couldn't come, but it would be nice to know that I was still invited. I'd see on Facebook what they would be up to and I'd be stuck at home. It would just have to be nice for them to say, well we are having a party tonight, if you want to come even if it's just for five or ten minutes just to say hi to everyone that's cool. There was none of that, not even oh we're having a party tonight. I just had to find out about it through Facebook or a friend*

*you're talking to saying oh we were at such and suchs place. I'd be like ok, cool (Amy).*

Many participants described how they felt quite socially isolated from not being able to do things with their friends because of the physical effects of their illness. For example, Megan commented,

*You know you missed out on some of the social interactions, cause your friends want to keep going and doing stuff and I'm just gonna sit down and have a rest or whatever (Megan).*

Similarly, Laura described how she felt she missed out on part of her adolescence of a result of having cancer.

*It was a huge deal. I mean I was stuck at home in a wheelchair and all my friends were out doing what teenagers do, like going out to parties and stuff, in a sense I missed out on my childhood and teenage hood, I couldn't go to parties and for that reason I don't, I'm not a party person now (Laura).*

By missing out on those social interactions in adolescence, Laura talked about how cancer had perhaps changed a part of herself.

Finally, those who developed cancer in adolescence described how they lost some of the increased freedom that came with being a teenager. Susan described the feeling of having that sense of freedom, then losing that freedom when dealing with cancer.

*When I turned 13 and then turned 14, it was I've got so much more freedom now, I can do this, I don't have to be confined at home all the time. Um, and then I got cancer and I was stuck. I was stuck in the hospital, I was stuck at home and I lost all the freedom that I had just gained (Susan).*

*Loss of identity*

For some participants, having cancer became an integral part of their identity and how others came to view them. While participants acknowledged that cancer had impacted and influenced who they became, they felt that some people could not look past the fact that they had cancer. Julie and Laura detailed two experiences below where they felt others defined them by their illness.

*I remember in high school someone introduced me to someone and she was listing off things that different people had done, she said this is Julie, she's had cancer and I'm like thanks, thanks. I'm glad that's my defining feature, and she's like oh I didn't mean it like that (Julie).*

*There's a lot of people who call me the miracle girl, and I'm like well I do have a name. It's definitely one of those things that never leaves you, it's who I am now, I'm the person who lived through cancer (Laura).*

For some participants, having cancer meant they would no longer develop and grow into the person they could have been, had they never had cancer. While participants such as Amy below, acknowledged they might never know who they might have been, they could acknowledge the loss of that potential identity.

*Why did I have to be this person? I wouldn't know what I would be like if I didn't get the cancer now, um what sort of person I would be, whether I'd be athletic or a druggie or whatever. It's just that difference of what I was, to what I am. If that makes sense. It was a grief thing. I did learn afterwards that it is a grieving process that you go through, your old self is now dead. You're not the person you would have been if you didn't get cancer (Amy).*

### *Loss of independence*

All participants discussed the impact of living with cancer through their adolescence. While some participants described their parents placing more restrictions on what they could do because of potential health risks, Amy spoke of her parents providing more freedom than before because of her illness.

*Before I was not allowed to do a lot of things that a normal teenager could do, my parents were quite strict, so I wasn't allowed to date boys or anything like that, um but as soon as I became sick it was oh Amy might not make it, she should be able to do those things. There were a lot more allowances for that side of things (Amy).*

As a result of their illness, several participants described having to master basic skills such as walking and eating. An example provided by Laura described having to

*Relearn how to walk after surgery, relearn co-ordination, the whole hand eye co-ordination thing or even brush my hair because I couldn't find my head (Laura).*

Similarly, Susan expressed frustration at having to learn how to feed herself again. Learning these skills meant that many participants had to rely and depend on others for help. For example, Laura spoke of her frustration at being at a age where she should be gaining independence from her parents, but instead had to rely on her mother for help with tasks such as toileting.

*I had to learn how to walk and talk, and learn how to use my hands again. I had to go to physiotherapy and relearn everything, literally from as a baby. I mean I didn't have to crawl, as much as in my head I knew how to walk, and I know how to talk and how to do everything, but I go to do it and it wouldn't work. And I'd be like wow, it was so frustrating, being a fifteen year old and your mum has to wipe your bum, this is just embarrassing. Your mum has to go to the toilet with you, and bath you and everything. I'm almost a grown woman, nearly an adult, come on. Why can't I do this myself? There's totally no boundaries between me and my mum now, she has seen everything (Laura).*

### *Meeting and losing friends with cancer*

Several participants discussed the impact of meeting others who had cancer who later passed away. For some such as Julie this brought up questions

relating to why they were the ones who survived, why they got a second chance at life when others did not, and what impact this had on their life moving forward.

Julie, for instance, spoke of experiencing survivor's guilt,

*For a long time I had survivor's guilt. For a long time I did think I don't deserve to live, I don't deserve to live, I don't deserve to live. And I spent a lot of that camp with a bereaved sibling and she only lost her brother in the last year and he didn't get the chance to live and I did, I realised that I was kind of throwing away this chance. It doesn't matter whether I deserved to live or not, I had this chance and I should take it (Julie).*

Furthermore, Julie commented that there is almost an understanding between people who have had cancer and who connect with others with the illness. She described them understanding what loss of a significant number of friends is actually like, something many of her own friends could not understand.

*Meeting others who had cancer was really good, and it's good that like being around other people who get the fact that you've lost a hell of a lot of your friends to cancer. Most of my friends, they've lost maybe one whereas like I remember one of my best friends asked me the other day, do you know how many people you've lost to cancer and actually I can't tell you the number, it's been such a long time, there's been so many people. So having that and some of the people in Canteen get the survivors guilt, like you survived this but all your friends died, or a hell of a lot of your friends died or they get that you like the guilt with it and so (Julie).*

While some people spoke about the negative side of losing those with cancer, some participants such as Susan were still able to identify ways in which meeting those people impacted their life in a positive way, even if only for a short period of time.

*There is a risk of someone you meet in Canteen passing away. But, I would, I actually think a lot of the other members feel the same way as I do, I would rather have a brief relationship, a brief and amazing relationship with one person than to go my whole life missing out on that one person who could have made an impact. And sometimes going to their funerals makes you realise how much of an impact they have had on you (Susan).*

## *Cancer as a time of growth*

All participants spoke extensively about how having cancer changed their perspective on the world, their future and challenged them to think about what was important in their life. They discussed how it made them think that they should be taking advantage of every opportunity they are provided with, as life is not a guaranteed thing. Tim spoke about how his illness made him question what was important in his life, but also helped him develop skills such as the ability to communicate with adults, which at thirteen he described as not being a necessary skill.

*It's given me a refocus in my life and different skill sets from what I had ` (Tim).*

### *Growing up faster*

A common subtheme within this topic was that cancer meant young people had to grow up faster and also had a sense of maturity that others their age perhaps had not reached yet. As Belinda commented below, while she used to worry about trivial things, following her diagnosis she has really considered what was really important to her in life. This perspective of having to mature quickly was also evident in Tim's account, who described the maturity as a necessary part of being surrounded by medical professionals during treatment and having to talk to numerous people about what he was going through.

*I think experiences like that, they make you grow up a bit faster and you mature and you have a new view on life. Like, you don't worry about the little things anymore, most of the time. I just feel grown up and a lot more mature and I don't worry about small things anymore. I used to be a perfectionist and you know I wanted everything, but I wanted everything to be a certain way but now it's like who cares, it doesn't matter. Like, you don't know what's gonna happen so you might as well enjoy life while you are here and get on with it. Stop being a dick and mucking around and just do what you want to do. That would have been good if I had learned that*

*even sooner because you know going through high school you worry about the stupidest things (Belinda).*

*You only get one chance so do everything at once, and its giving me a sense of being able to talk to adults and being a bit more mature, compared to my peers especially as I spoke to adults and had to interact with them in hospital, and I was surrounded by adults. I'm able to talk to them and I'm able to talk to my friends and peers and so it's given me that sort of interaction and in a sense its matured me and I'm kind of happy with that (Tim).*

### *Learning to take every opportunity*

Participants spoke about how when they went through cancer, they started seeing things in a new way. When reflecting on how cancer had changed their perspectives on life, one theme that was evident across every interview was that cancer taught them to take every opportunity in life. For example, a number of participants spoke about people they felt were not making the most of their lives. This was evident in Belinda's account below.

*A lot of people even my age now are still mucking around and you know they don't know what to do, they're out there, out in town you know, playing up or mucking round, getting drunk whatever and I just look at that now and I'm like that's so stupid. That's such a waste of time, why are you doing that? It annoys me a little bit, umm, but yeah I guess it's just taught me what is important and that you need to focus on that instead of doing nothing or wasting away being an idiot. You need to get on with it. You don't know what will happen tomorrow (Belinda).*

Belinda emphasised that life is not guaranteed, and this concept of the value of life was also evident in a number of other statements made by participants.

*It's that view of living life to the fullest, like I don't have that long, even though I hope I still have like 70 years. But I'm going, I haven't got that long, keep going (Tim).*

*Like tomorrow is not guaranteed, that's the biggest thing. That you never know what's going to happen so it's really important to live your life to the fullest every day, that's probably the main thing (Julie).*

*You don't take things for granted, it's not just what your body can do, it's things for granted, you didn't do it any other time so why not do it now? Why wait until you're older, why wait until you lose life. Why wait to live your life? Life is made to be lived, so you have to live it (Susan).*

For some participants such as Liam, having cancer led them to realise that they are not invincible which can be a common misconception for young people. This sense of invulnerability was challenged when Liam was given a diagnosis of cancer. As described below, this realisation did make Liam question what he was hoping to achieve in his life and that he should make more of an effort to reach those goals.

*Cancer made me more determined to get things done in life. I think it made me a bit more sure of who I am and who I want to be. I think it was mainly sort of how easy life is to lose, like you always think that can't happen to me, then it does and so I think especially with other things, people think no I won't have a car crash, I won't have this happen, it's me of course it won't happen. I learnt that actually things can and do happen (Liam).*

While cancer was seen by most participants as a negative experience that they would not wish to live through again, several participants clearly stated that they believed having cancer taught them how to find good things in bad experiences and the importance of making meaning out of adverse life events. Tim commented,

*It's about seeing that there are disadvantages, but the opportunities outweigh the disadvantages (Tim).*

This change in perspective has also helped change how they have viewed future challenges they have had to face. This is evident in Amy's account as detailed below.

*I've been to the point where it couldn't get any worse, so you learn to make positives even in the dark times. You find the glad parts, the positives. Whether it be the car broke down, really again, but then you go you can be glad you can drive this, because five years ago you couldn't drive and there was no way you would have ever been able to drive again and you're driving it now and you've got a car. just little things like that, so you burn the toast for breakfast in the morning, and you think why did I have to do that because I'm in a hurry and late for work, but then you go at least I can feed myself now, I can make my own toast. Why does my fork have to be crooked, well at least I can feed myself with a knife and fork now. Just little things, and you think well ok I can see the positive in that, rather than looking at the bad things. Maybe learning that comes easier to someone who has been through an experience like that. Not necessarily just cancer, but a hard tragedy or experience where you end up learning that you can find good things in the bad (Amy).*

#### *Change in goals and priorities*

For many participants, having cancer meant that they had to rethink their current focus and priorities. An example provided by Tim was,

*As I went on, I had my treatment and there was no focus on girls who anything like that, or other teenage aspects such as discovering new things. It just wasn't that important (Tim).*

Tim emphasised that the goals he had prior to getting sick such as developing relationships with girls were no longer important. Following treatment, some of the physical effects of the disease meant that participants had to rethink what they could realistically achieve and what they had to work on. For Tim, his focus, which had been previously on girls, moved to a focus on recovery.

*I finished with the cancer and then I had to get healthy so I focused on getting healthy and getting back strong and I ended up walking. After my treatment, walking from my couch to the toilet which was five ten metres away was like, wow! you did a big thing today! So I had to build it up from*

*walking to the house to the end of the street and then building it up and that was my main focus then (Tim).*

Similarly to Tim's change in what was important to him, Julie also recalled a time where she felt that her priorities were different from people her own age as described below.

*I didn't care about guys for a really long time, um like all my other friends were and I was like Nah. I don't care. I remember Prince William when he came to New Zealand and he went up to Starship and I remember all my cousins, saying aww was he really hot in person? I was like uh, I don't know? It was like obvious that I was fighting for my life so I didn't care if a guy liked me or not. I didn't even think about it (Julie).*

Similarly, one participant commented that having cancer meant she placed all her focus on getting healthy and was unable to do certain things that were expected of adolescents such as challenging authority and challenging rules.

*It's kind of expected for a teenager to break the rules. Pushing boundaries and things like that. Obviously being a patient and being sick all the time, you're not expected to break the rules and you kind of can't, because you're too busy trying to stay alive (Amy).*

Some participants expressed frustration and annoyance towards their peers who, they believe, are focused on the wrong things in life. For example, both Megan and Amy described how their experience of cancer made them realise that there are far more important things in life than focusing on trivial details. They also both discussed the level of maturity they had reached as a result of experiencing cancer possibly contributing to this difference.

*I think I grew up a lot faster than other people. Like I said it really changed my perspective on things so like, my friends are going to town and are worried about their hair and makeup and you know, whether they're wearing the right shoes and I'm like well, my hairs not too bad today, it's long, it'll do. And oh you know, do I fit in this dress and I think oh yes, I finally fit in my dress again, it's not falling off me (Megan).*

*When they start grumbling about something, I think oh come on, get a real problem. I've come to a point where I don't have the time or patience for people my age anymore (Amy).*

Some participants such as Julie, acknowledged that her illness had shifted her focus from more self- centred to more concern towards how others are feeling. This was evident in her statement,

*Well I guess before I got sick, I was a lot, I was probably more focused on myself and um, cancer made me think about others a bit more. Cause like the hardest part of cancer was for me, wasn't all the different shit that happened to me, it was my family having to deal with it, cause it destroyed my family like quite a bit and so I wish, I'd like to take that part away (Julie).*

## *Chapter Four:*

### *Discussion*

The overall aim of this research was to examine the impact having cancer in adolescence had on relationships with others including peers and family members. The purpose of this research was also to explore where young people found support during their illness and what coping strategies they used to adjust to their illness and treatment. This was further explored by asking what young people perceived would have been beneficial or helpful during their experience of cancer that they did not receive. The final aim was to explore how having cancer affected the developmental tasks of separation and individuation, and identity formation.

The results of this study presented in the earlier section indicate that there were two overall themes that seemed to encapsulate the experiences of the adolescents. The first overall theme was the importance of coping strategies and what helped during their illness. Participants identified the use of three common coping strategies: the use of humour, acceptance of the illness and distraction as a means to distance themselves from their illness. Parental support was identified as an area of importance in addition to receiving social support from siblings. Meeting those who had also experienced cancer was also identified as useful by participants. Participants emphasised that people who had experienced cancer shared an understanding that others simply did not have. There was also an emphasis on the importance of the provision of information, particularly with regards to receiving information later in their illness, rather than when they were diagnosed. This was identified as a time when some participants felt overwhelmed with being given information.

The second overall theme that emerged from the participants' experiences was that life will never be the same after cancer. This was a sentiment expressed by all participants and they described numerous ways their lives have been changed by their illness. While participants commented that there seemed to be a focus on supporting the young person during their illness, many felt that they needed more support following their recovery which was not always provided.

All participants described negative ways in which their relationships with peers had been affected and many felt that people did not know what to say, which created feelings of frustration and irritation for the young person. Cancer was described by participants as a time of loss, where they lost a part of their identity, they lost their independence, and they missed out on a number of opportunities. They also acknowledged the guilt that they felt when peers they had met with cancer passed away. Finally, all participants identified ways in which their experience of cancer had helped them grow and develop. Many commented that they had matured faster because of what they had been through and were more likely to take advantage of opportunities they were given. Participants also emphasised that they felt their goals and priorities had changed significantly since having cancer and often felt their goals were not aligned with those of their peers.

#### *Different ways of coping with cancer*

How young people coped with cancer was an area that was specifically asked about in the interviews. The participants identified and described a number of strategies that they used to cope with their diagnosis and the resulting impact of their illness. Decker (2006) emphasised the importance of effective coping for young people with cancer, as it not only provides relief in the short term, but can also contribute to positive cognitive, behavioural and social outcomes in the long term.

The use of the varied coping strategies as described by the participants in the present study is consistent with the literature reviews by Decker (2006) and Compas et al. (2012) which suggests that adolescents with cancer and young people with chronic illnesses in general, utilised a number of differing coping strategies. Many of the coping styles described by the participants in the present study were indicative of problem focused strategies such as seeking illness related information, or emotion focused strategies such as acceptance of the illness. The reported use of distraction was an example of an avoidant strategy as discussed in Decker's (2006) review which suggested that some young people cope by minimising the impact of the stressor or attempting to avoid the stressor. Some examples of distraction provided by the participants in the present study included

reading books, going to the gym, watching rubbish television and keeping their minds busy by focusing on other things such as planning a party.

Literature in this area has suggested that those who use avoidant coping strategies such as distraction and trying to distance themselves from current stressors have higher levels of distress following a cancer diagnosis. This includes increased levels of depression and anxiety when compared to individuals who use less avoidant coping strategies (Turner-Sack, Menna & Setchell, 2012). Reasons for this difference could be that coping strategies might not work for those who are more distressed, or it might be because people who are more distressed need to distract themselves more.

In the present study, using distraction strategies appeared to help some of the participants escape from the potential fears or worries they may have had, particularly during the treatment stage of their illness. Furthermore, participants' descriptions of their experiences using this particular coping strategy did not suggest a link between their use of distraction and problematic outcomes. It is important to acknowledge that this study did not specifically examine participants' perceived levels of distress following a cancer diagnosis. This may explain some of the differences between this study and the literature as perhaps the young people in the present study were less likely to acknowledge levels of distress. In addition, no participants identified the use of more maladaptive or self-destructive avoidant strategies, such as denial, substance use, behavioural disengagement or the use of withdrawal that have been found to be associated with higher levels of distress (Decker, 2006). It appeared that participants' avoidance was limited to the use of distraction as a means to distance themselves from worrying about their illness, rather than denying that it was happening. This may have meant that they were still able to deal with the challenges associated with the illness that others who also use substances or withdrawal as a means of avoidance may not. In addition, many participants were also able to identify other styles of coping that were used alongside distraction, which will be discussed later in this section. It is possible that the exclusive use of avoidant strategies might be a red flag for clinicians to attend to building up the young person's repertoire of coping resources.

Distracting themselves from the illness and treatment and keeping themselves busy is consistent with two themes that emerged from a study by Weekes and Kagan (1994) examining coping strategies at different stages of the cancer diagnosis for 13 adolescents. They found that the use of avoidant style techniques were particularly common prior to the completion of treatment, which was also a similar finding in this study. For example, one participant commented how he found that going to the gym was a really useful way to pass the time when he was having chemotherapy treatment, even though he reported that medical professionals had advised against exercising when completing treatment. One participant even commented that she could not even bring herself to say the word cancer when telling others, which was likely another type of avoidance.

Using humour as a coping strategy was discussed by three participants. Juvakka and Kylma (2009) suggested that the use of humour provides adolescents the ability and courage to escape from their situation and that humour gives young people a way to make the situation more light hearted for their peers. It was interesting that the use of humour was identified by the authors as a means of escape as there could be a link between participants using humour and the use of distraction as discussed earlier. The usefulness of humour when talking to peers about their illness was acknowledged by one of the participants, as she described that it made the situation less uncomfortable. However, she also emphasised that you have to be careful who you make the jokes to, as some people do not understand it. In addition, another participant discussed how she felt that using humour to make it easier to deal with the illness was a strategy that would not last forever and emphasised that eventually, you do have to deal with your stressors.

Juvakka and Kylma (2009) posit that the use of humour is linked to the concept of hopefulness. In their study of six adolescents, they found that in addition to spirituality and a positive attitude, the use of humour was a factor related to an increased sense of hope. Literature has emphasised the importance of hopefulness for young people with cancer as higher levels of hopefulness have been found to be related to a positive sense of wellbeing, commitment to treatment and can aid in the transition to regain some sense of normalcy (Cantrell & Lupinacci, 2004; Abrams, Hazen and Penson, 2007). While hopefulness was not discussed in any of the interviews explicitly, reframing negative thoughts into positive thoughts was described by one of the participants as a useful way to

reconceptualise his experience of his illness which could be indicative of a more hopeful way of thinking about his illness.

In addition to participants describing the use of humour and distraction to cope with their illness, several participants reported that how they coped was to accept their diagnosis and instead focus on what they could do. This style of coping seemed to be indicative of both a problem focused and emotion focused strategy. Carver, Weintraub and Scheier (1986) defined problem focused coping strategies as strategies aimed at seeking information, problem solving and actively doing something to change the situation creating the stress. Two participants acknowledged that since they had no ability to change their situation they felt there was no other choice but to deal with the effects of their illness and they found practical ways to do this. Several participants described how they independently searched the internet for information on their illnesses, which one of the participants described as empowering to be able to gain some control again. Emotion focused coping strategies are aimed at reducing the emotional distress associated with the stressor, rather than dealing with the actual stress (Band & Weiz, 1988). The use of support seeking from parents and peers to help ease their distress was commonly identified by participants, which is one strategy of emotion based coping that has been described in the literature as used by adolescents with cancer (Band & Weiz, 1988).

This finding emphasises that adolescents with cancer utilise a variety of coping strategies to adjust to a cancer diagnosis. Therefore, for people working with this population, information about different coping strategies and their outcomes might be useful to ensure that the young people are aware that there are a number of ways to cope. It is important for each young person to find a coping strategy that meets their particular needs.

### *The importance of social support*

Nearly all the participants in this study described the usefulness of social support during their illness, including support from others who had lived through similar experiences, parental support and support from siblings and peers. According to Haluska and colleagues (2002), perceived levels of social support

can be one of the most critical factors that influence whether an individual is able to adapt successfully to life changes.

Three participants described that friends actively trying to include them in social activities such as inviting them to parties, coming to see them in hospital or visiting them at home was one of the factors that best helped them cope with their illness. One participant commented that even receiving a text message was enough, just to show that her friends were thinking about her. Acknowledging the importance of social connectedness and appreciating peers making an effort to keep in contact during their illness was consistent with previous studies such as by Woodgate (2006). This study found that when adolescents were trying to re-integrate into their social world following completion of treatment, peer support had a significant impact on how well the adolescent coped. The findings in the current study highlight that in general these participants were willing to seek and accept social support. This is a promising finding as previous literature has emphasised that positive social relationships following a cancer diagnosis can result in improved reports of quality of life and can decrease psychological distress and uncertainty associated with adolescent cancer (Neville, 1999).

The importance of social support is particularly imperative for this age group where there is an immense pressure to develop peer relations and start forming intimate relationships. Adolescence is also a time where acceptance by one's peers is crucial (Abrams, Hazen, & Penson, 2007). A cancer diagnosis can be a significant challenge to obtaining this acceptance, as young people can feel extremely isolated and different from their peers. Therefore, having social support to minimise these feelings of isolation and not fitting in have been found to be extremely important (Kyngas et al., 2001).

Literature in this area emphasises the importance of social support from peers; however, one participant reported that during his time in hospital in particular, he did not want his friends to come and visit him. According to the participant, this was because he did not want his peers to perceive him to be weak and vulnerable. Although this reluctance to accept social support from peers was only expressed by one participant, it is important to consider alternative avenues of support for individuals who do not want social support from their peers during particular times in their treatment. The participant said that for him personally, he

chose to rely on support from his immediate family. This is a good reminder that it is important to consider the preferences of an individual, and not assume that all social support is desired.

Research by Mitchell et al. (2006) and Wakefield et al (2003) have emphasised the benefits of forming and maintaining friendships with peers who have also experienced cancer. The usefulness of meeting others who have been through a similar journey was a sentiment expressed by five of the participants. Participants described having a level of understanding among others who have had cancer that their own peers and family did not have.

All participants in this study emphasised the importance of support they had received from their families, and in particular their parents. They also all described how having cancer brought them closer to their families; this is consistent with research by Wakefield and colleagues (2013) who found that all 19 participants they interviewed reported that that they felt an increased closeness and intimacy with family members after completion of treatment in contrast to before having cancer. The importance of parental support for adolescents with cancer has been found in a number of studies. For example, studies by Wakefield et al. (2013) and Stegenga and Ward-Smith (2009) found that adolescents with cancer reported their parents to be their primary source of support throughout their illness. A finding of the present study was that the reported primary source of support was dependent on the gender of the adolescent. For example, generally the female participants were more likely to describe how they felt their relationship with their mother became closer throughout the course of their illness, while the two male participants primarily discussed their fathers, when talking about parental support.

Numerous studies have looked at the psychological effects on parents of having a child with cancer (Allen, Newman & Souhami, 1997; Norberg & Boman, 2008). Allen et al. (1997) found that both mothers and fathers of children with cancer have higher levels of anxiety when compared to normed samples and that 27% of mothers had moderate to severe levels of depression following their child's diagnosis. Although examining levels of parental distress following a cancer diagnosis was beyond the scope of this research, several participants acknowledged the distress their parents felt during their diagnosis. One participant

suggested that this distress was related to the powerlessness her mother felt over being unable to do anything to change the situation. The two male participants commented that seeing their parents distressed and upset was extremely difficult, and they wished that their parents and in particular their fathers, could have appeared stronger. One possible reason for this reluctance to seeing their parents' distress could be related to the adolescent feeling guilty and the perception that they have caused this distress. It could also be related to the families desire to shield and protect each other from painful information, particularly in the diagnosis stage (Whyte & Smith, 1997). In addition, the adolescents may find it significantly harder to distance themselves from their fear and illness, if they see their parents becoming upset. It may be that parental distress may make the situation more real for the adolescent and might challenge their avoidant coping strategy as discussed earlier. Perhaps this means that parents should find a safe place to express their feelings, but might (for the time being) shelter their children from their distress as much as possible.

In addition to parental support, participants in this study emphasised the importance of the support they had received from their siblings. This is consistent with findings in a literature review of adolescents and cancer by Whyte and Smith (1997) and recent research by Wakefield et al (2013) who found that support and the relationships with siblings were invaluable during their illness. In general, participants described their siblings support as constant and felt they could rely on their siblings to be around, whereas this was not always true of some of their peer relationships.

In addition, some participants also expressed feelings of guilt and frustration at feeling responsible for what their siblings had to go through. Alderfer et al (2009) acknowledged that with regards to the psychological impacts of a cancer diagnosis, siblings are the least well researched out of immediate family members. Participants described that their siblings often struggled to find a balance between continuing with their own lives such as going to school, spending time with friends and playing sports, while at the same time worrying about their sibling and having numerous hospital visits. Some participants reported that their siblings felt that they could not express their own distress, for fear of drawing attention away from their ill sibling and appearing selfish. Although this information was from the perspective of the adolescent who had

cancer, not their healthy sibling, this finding is consistent with research which has found that common themes in qualitative studies with siblings of those with cancer include a loss of attention, changes in family relationships and disruption to routine (Alderfer et al., 2000).

Manne and Miller (1998) found that the relationship between siblings can become strained if the healthy sibling feels they have to take on additional work around the home or to make up for absent parents. While participants described significant changes to their siblings' lives, such as having to live with other family members while their sibling was having treatment in another town, living on their own and having to get to school on their own, there was no evidence in the interviews that suggested that participants felt their relationship with siblings was negatively affected by their diagnosis. In fact, most said that having cancer actually brought them closer to their siblings. One potential reason for this difference was that three participants reported that even after their recovery, they had still not talked properly to their siblings about their illness and how it affected their sibling. Whyte and Smith (1997) suggested that family members of a young child with cancer will all try to protect each other from what they personally are experiencing. Perhaps the healthy sibling is still concerned with appearing to take away from the sibling who had cancer, even after the cancer has gone. While studying the impacts of having an adolescent sibling with cancer from the siblings' perspective was beyond the scope of the research, further research in this area could be useful to examine this with a particular focus on the perceived unmet needs of siblings of adolescents with cancer within a New Zealand context.

These findings highlight a need for professionals and those working with young people with cancer and their families to be aware of the impact their illness may also be having on siblings and parents. This is particularly important when findings from this study and previous research has found that support from siblings and parents is considered invaluable by the adolescent with cancer throughout their illness. If the sibling or parents are not equipped to cope with their own distress or issues, this could influence their ability to support their child or siblings. Professionals should focus on how to identify family members who may be struggling to support a young person with cancer and also prepare siblings and parents for what they can expect on the cancer journey.

*The provision of information about cancer is important at the right time*

When asked about their understanding of their illness and treatment and the provision of information, a number of participants emphasised how important it was for information to be provided at the right time. Three participants reported that receiving information in the early stages of their diagnosis was not a good time and they felt overwhelmed, as they were still trying to come to terms with what they had been told. This is consistent with previous literature which has emphasised the need and desire for adolescents to receive information about their illness at the right time and in a way that was easily understood (Juvakka & Kylma, 2009). Furthermore, Palmer et al. (2007) suggest that an adolescent's cancer journey is influenced by their current developmental stage. For example, while some adolescents feel prepared to cope with all the information regarding their illness and treatment, others felt overwhelmed and fearful when given too much information at once (Palmer et al., 2007). Many participants expressed that they were comfortable with their parents being told more information than they were about their illness. That was particularly true in the time immediately following their diagnosis. However, participants felt that as time progressed they wanted more information when they felt they were better equipped to deal with it. This finding highlights a need for medical professionals to consider at what stage during the illness it is most appropriate for the young person to receive information, so that they do know enough about what they can expect, but also so that they are not overwhelmed. In order to work effectively with this group, professionals have to keep in mind the individual developmental level of the youth.

All participants acknowledged the importance of receiving illness and treatment related information. This finding is consistent with the normal developmental tasks of adolescence which include seeking independence and wanting to be actively involved in making decisions around their own body (Whyte & Smith, 1997). This finding is also consistent with studies such as Hedstrom, Skolin and von Essen (2004) that found that adolescents with cancer had identified the need for accurate information from medical staff as an important aspect of health care. Previous literature has suggested that when reflecting on their illness, adolescents perceived that they were not given the amount of information they wanted. For example, Dunsmore and Quine's (1995)

study that examined informational needs of Australian young people found that approximately two thirds of the participants wanted more information during their illness. This information included how likely they were to have cancer again and long term effects such as the possible effect on fertility. While the participants in the current study reported that at times they did feel excluded from receiving information, generally they were happy with the quality and amount of information they received. This is a promising finding as studies have shown that young people who receive open and honest information regarding their diagnosis and the prognosis of their illness are at a lower risk for depression and anxiety, than those who do not (Last & van Veldhuizen, 1996).

#### *Life will never be the same after cancer*

Some participants emphasised that following the completion of treatment people assume that since the cancer is gone and they are better, that they no longer require as much support and help. However, according to some of the participants, following the end of treatment is actually the time where they felt they needed a considerable amount of support. This was because they were having to navigate and re-enter a social world that they have been absent from for a long amount of time, and in that time the social world may have changed. Now that they are not focusing on their illness and becoming healthy again, participants described that they have more time to think about and deal with the possible long term psychological and physical effects of their illness and treatment, such as infertility. This finding is consistent with the literature, which suggests that most adolescents found there was minimal support available for psychological issues following treatment. In a study by Palmer and colleagues (2007), one participant commented that most professionals are concerned with helping the individual get better, but there is limited support available beyond that point.

Most participants in this study were associated with support services such as Canteen, who do offer such support following completion of treatment. However, for young people who are not connected to services such as Canteen, this could pose a challenge of having their psychological needs met. This finding highlights the critical need for support for young people with cancer past the

completion of their treatment. It is imperative that young people are aware of and are able to access support and services if they need to. It may be that some of the effects of the illness that these young people are going to have to deal with are not evident until well after the completion of treatment. For example, a fourteen year old may not be as concerned with finding out that she may be infertile as a result of treatment in comparison to a nineteen year old who was thinking about starting a family in the near future. Therefore, accessibility to support and services needs to remain an ongoing and open option for young people through their illness, immediately after completion of treatment and throughout their lives.

For participants in the present study, believing that they could regain some small part of how life was before and that people would not change how they treated them was reported to be extremely helpful. Several participants emphasised that they wished people would not treat them as vulnerable or something that could be easily broken. As adolescence is a developmental period where acceptance by peers and the development of peer relations is so crucial, it makes sense that young people would express a desire to return to their old life where they did not feel different or isolated from all their peers (Conger & Galambos, 1997; Stegenga & Ward-Smith, 2008). This finding is also aligned with Cantrell and Conte (2009) and Rechner's (1990) assertion that following cancer, it is common for adolescents to want to return to their lives and regain some sense of normalcy.

However, as Conger and Galambos (1997) emphasised and as was found in the present study, regaining normalcy and returning to their old lives is something that young people continue to identify as challenging. This finding highlights the importance of helping young people with cancer regain some part of their life that they had prior to their diagnosis. When the young person feels ready, they could be encouraged to reconnect with previous social groups, sports team or clubs or advised of other possible avenues that may be appropriate to help rebuild social connectedness. They could also be taught ways to effectively communicate with others about the way they are being treated. This could be particularly useful if they feel frustrated or annoyed at being perceived as vulnerable or weak, as was the case for several participants in this study.

Many of the participants identified and discussed the physical effects from their cancer and their treatment for cancer. While this thesis was not focused on the physical effects of cancer in particular, how these physical effects impacted the young people's lives and the psychological impact of these effects were explored. Some participants emphasised that cancer has had a considerable impact on their health and their ability to engage in certain activities such as playing sports. This was consistent with findings by Mattsson, Ringner, Ljungman, & von Essen (2007), who found that upon reintegration to school, many young people felt isolated because they could no longer participate in activities that their peers were involved with. This inability to participate in sports and other activities meant that the adolescents found it difficult to reconnect with their peers socially and felt increased levels of isolation.

In the current study, participants cited effects such as fatigue and dealing with the physical scars from their illness as causing concern and impacting on both their desire and ability to engage in social activities with their peers. One participant described trying to hide scars from her surgeries for fear of what other people might think or say. This is consistent with research by Manne and Miller (1998) which found that some adolescents reported that physical effects of treatment, such as hair loss, affected their self confidence and decreased their interest in engaging in social activities with peers. This finding suggests that young people who are reintegrating into their social world following treatment, could perhaps be advised of alternative activities to increase feelings of social connectedness. Young people could also be taught coping strategies or to rehearse what to say if people did comment negatively about the physical effects of their illness. In addition, professionals, family members and others working with these young people should consider levels of self esteem and social isolation in young people and their possible relation to body image and feelings of self-consciousness.

### *Relationships change*

Having cancer in adolescence can lead to both emotional and physical isolation from peers, which can have a serious impact on social relationships. This has implications for adolescents with cancer as these social relationships play an

extremely important role in the development of autonomy and being able to identify personal values crucial to the transition from young adult to adulthood (Zebrack, 2011; Manne & Miller, 1998).

When asked about the impact on their relationships, all the participants in this present study described positive and negative ways in which their relationships had changed. Some participants also emphasised that following their diagnosis, they were not given the same level of expectation that others had and this was evident in both the home and school context. There was no literature identified that described in detail how expectations for young people with cancer were lowered following their diagnosis. However, that does not mean to say that this finding is specific to this particular study. Perhaps, the area has not been a focus on research yet. A study by Overbaugh and Sawin (1992) examined levels of adolescent's self esteem following cancer and also future life expectations from the perspective of the young person and their parents. Overbaugh and Sawin (1992) propose that parental attitudes and expectations will influence the adolescents and how they set goals for the future, but also found in their study that parents generally believe young people are capable of attaining their goals. In the study there was no evidence of lowered expectations for their child. Interesting follow up research would be to examine if there is a difference between parents' and young people's perceptions of changes in expectations, and more exploration of the issue of expectations for young people post-cancer. For example, lowered expectations may emphasise to the adolescents who have had cancer that they are still different, to their peers, even after the completion of treatment. This could perpetuate feelings of isolation.

A finding highlighted in this study was that many participants believed they lost a number of friendships throughout their cancer journey as their friends did not know what to say or how to support their friend. Some participants emphasised that their peers often struggled as they could not understand what they were going through. In addition, some participants described their frustration and annoyance at people who would stare at the obvious effects of their illness, but would not ask questions. It appeared that cancer was a taboo topic, that many people are afraid to talk about. This finding was consistent with the assertion of Palmer et al. (2007) that it is common for relationships to change following a cancer diagnosis, as many friends do not know what to say or how to react. In

addition, Palmer, Mitchell, Thompson, & Sexton (2007) reported that some adolescents with cancer noted that their friends tried to avoid them or acted uncomfortable around them. For these young people, this was extremely distressing and confusing. The literature suggests this frustration between adolescents with cancer and peers can sometimes continue in a cycle, as adolescents with cancer often find it difficult to handle the attention and questions from their friends, regarding their illness (Palmer et al., 2007). While the participants in this study reported that they were happy to discuss their illness and answer questions, there were some concerns expressed about talking about their illness with peers. For example, one participant commented that she felt that talking about her illness made her feel like she was a “downer” and lowering the mood of the group.

Studies have emphasised the importance of quality relationships for adolescents experiencing cancer. Neville (1999) concluded that positive social relationships can result in improved reports of quality of life and can provide an adolescent with an increased ability to cope with stress. Having strong social support has also been found to decrease psychological distress and uncertainty associated with adolescent cancer. Peers also have a crucial role in helping the adolescent with cancer reintegrate back into their social world (Woodgate, 2006). Reflecting on the limited literature examining education and support needs of the peers of adolescents with cancer and this present study, there appears to be an unmet need in terms of adequate support and education for peers of young people with cancer. It appears there is a dilemma for peers supporting their friends with cancer. There is limited research providing information on what peers should do or what the young person with cancer would like them to do. However, it is likely that this is an important topic and research examining how to foster improved interactions, whether by helping the youth to ask for what they need, or educating the peers, is needed. This was addressed by one of the participants in the present study, who felt that access to support and information could have helped some of her friends cope with the situation more effectively. By providing peers with information and support, it would be hoped that they could feel more comfortable with what to expect and confident to support their friends through their cancer journey. Some ways this information could be given could include sessions at schools if a young person has been diagnosed or for a group of friends to meet

someone who can answer their questions and allow them to address their concerns. If an in-person intervention is not available, flyers with some basic information for friends of young people with cancer could be useful.

While there was acknowledgement of some of the negative changes to the way people treated them, some participants emphasised that some of these changes had been positive. There seemed to be a unwritten rule as one of the participants described, “you can’t mock the cancer kid”. This was expressed by two participants, with one even commenting that following her diagnosis she was no longer bullied at school. In addition, participants described a stigma towards those who did direct negative comments towards the adolescents.

#### *Impact on intimate relationships*

In addition to changes in peer relationships, some participants described that their intimate relationships had been significantly impacted by their illness. Participants reported that fatigue and other physical effects of cancer and treatment meant they were not able to spend as much time with their partner as they had done prior to their diagnosis. This impact on intimate relationships has been found in other research such as Evan, Kaufman, Cook and Zelter’s (2006) study, which found that young people with cancer are more likely to avoid or are less likely to establish intimate relationships. Some possible reasons for this reluctance as identified in the literature includes low levels of self-esteem and body image concerns (Even, Kaufman, Cook & Zelter, 2006). In addition, Abrams, Hazen and Penson (2007) posit that the development and interest in intimate relationships depends on having a positive sense of self and body image, which are both challenged during treatment. These factors were not described by the participants in the present study who discussed the effects of their illness on their intimate relationships. While some participants did describe an increase in feelings of self-consciousness following treatment, they did not associate this self-consciousness with problems in their intimate relationships. Instead, one participant cited that feelings of guilt for holding her partner back from engaging in activities was the primary reason she ended the relationship. She commented that being advised not to engage in behaviours typical in a relationship such as

kissing or hugging was really hard on their relationship, especially as she felt responsible for those restrictions.

Two participants reflected that prior to their diagnosis they had started to become more interested in the opposite sex, but continuing to develop intimate relationships was just something that was not important when they were facing a cancer diagnosis. This is consistent with findings from a German study by Dieluwweit and colleagues (2010) who found that when compared to healthy controls, female survivors were less likely to have achieved tasks associated with psychosexual development, such as having a boyfriend. This suggests that some adolescents may reach developmental milestones after their healthy peers, simply because it is not something of importance while they are recovering.

Another participant commented that her future intimate relationships would be affected as the treatment for her illness meant she was now infertile. She reported that this was something she has to be aware of before entering any new relationships and that she has to be open with any potential partners about her inability to have children in the future. In addition, many participants described that when they became sick they were no longer focused on building relationships, instead their main priority was to get healthy.

For adolescents with cancer, this impact on intimate relationships can have implications for a number of areas such as psychosocial development. For example, Erikson posited that young adulthood is a stage where the challenge is for individuals to develop the ability to form close, intimate relationships (1968). Since starting to develop intimate relationships is an important achievement during adolescence, and many adolescents spend much of their social energy on thinking about, talking about, and engaging in romantic partnerships, these young people may find they feel different from their peers. Therefore, it is important to educate young people with cancer about how a cancer diagnosis may impact their development of intimate partner relationships or how their relationships may be affected. Young people could be taught strategies and encouraged to practice ways to comfortably bring up and discuss issues relating to their illness or treatment with future partners. For those in a relationship, talking to both the adolescent with cancer and their partner may be a useful way to inform both parties about what might be expected.

### *Cancer as loss*

For participants, cancer was a time of loss and a grieving process. Participants described missing out on a number of social opportunities throughout their illness and even following completion of treatment. Many young people reported that the physical effects of their illness such as fatigue and some peers not inviting them to social events were some reasons they missed out on doing things that their friends were involved with. This is consistent with studies by Haluska, Jessee and Nagy (2002) and Zebrack (2011), who found that adolescents with cancer commonly miss out on experiences that their friends are having, including dating, leaving home, going to university, getting married or having children. Issues relating to fertility were particularly pertinent for one of the participants who was told that as a result of her treatment she would no longer be able to have children. Literature in this area has found that infertility is a major concern for adolescents with cancer. Oosterhuis et al. (2008) found that approximately 43% of adolescent oncology patients were concerned their treatment may make them infertile. This again emphasises the need to continue to support adolescents following the completion of the treatment, as many of the effects of their treatment are going to have long term effects on their lives.

According to Abrams, Hazen and Penson (2007) a crucial developmental task in adolescence is to gain autonomy and independence. For an adolescent with cancer, gaining this independence can be made difficult by having to rely on parents for emotional support and practical assistance such as being taken to hospital for treatment and checkups. This is consistent with reports by participants in the present study who commented that they did require parental assistance for a range of things such as being taken to checkups, helping them reconnect with friends. One participant reported that her mother helped her with toileting and bathing.

Manne and Miller (1998) propose that this conflict between wanting independence, yet requiring help can create problems between the parent and child. These problems can be perpetuated by parents becoming overprotective of their child and limiting their activities. While some participants did describe some restrictions their parents put on them after they became sick, no participants

reported that these restrictions had negatively affected their relationship with their parents. In contrast to the findings by Manne and Miller (1998), one participant even stated that her parents gave her more freedom by letting her date, which she did not believe she would have been able to do if she had not become ill. She believed that they allowed her to do these things because they felt that she should get to experience everything she can, as they realised that life could easily be taken away.

There has been limited literature examining survivor guilt from the perspective of adolescent cancer survivors. However, as found in this present study, this was a common issue amongst adolescents who had met others with cancer. While there are a number of benefits of meeting others who have cancer such as a shared understanding, there is also a chance that these young people could pass away. Participants described a dilemma between wanting to acknowledge their own recovery, but remembering that someone they cared about had not recovered. One piece of literature that discussed survivor guilt was a handbook for cancer survivors that had a brief outline of survivor guilt and provided two quotes (Keene, Hobbie & Ruccione, 2012). However, there were no specific studies on this topic or how survivor guilt affects a young person who has recovered from their illness. The difficulties participants described with survivor guilt pose a challenge in that the young person wants to grieve for the losses that they have personally experienced in their life such as loss of opportunities, but at the same time feels guilty that they have gotten better when someone else did not. Further research in this area would be extremely beneficial to help develop ways for the young person to deal with the loss of their friend, while also feeling that they can celebrate their own health. For professionals or agencies working with young people it is important to be aware of the conflict this guilt may bring up and to provide ways or coping strategies for the young people to work through this guilt. One way to do this could be to help these young people to make meaning from their experience and think about how they can apply what they have learnt to their life and how they may also help others.

### *Loss of identity*

There is agreement within the literature that the development of identity is one of the key tasks of adolescence and is crucial to the transition to adulthood (Erikson, 1968). Recent literature has sought to examine how an individual adapts their identity as they transition from an individual with cancer to a cancer survivor (e.g. Cantrell & Conte, 2009; Jones, Parker-Raley & Barczyk, 2011). Findings from these studies suggest that even though cancer survivors want to regain some sense of normalcy, they often struggle and find it difficult to return to their old lives. For example Cantrell and Conte (2009) found that a theme that emerged from their study included the young people having to “reinvent the self”. The authors posited that the young people struggle to regain who they used to be and have to establish a different identity. This fits with the experience of one of the participants in this study who described that she had to grieve for her past self, as she felt her old self was dead. This finding highlights that after completion of treatment, survivors face a dilemma between wanting to return to their pre-illness life and to feel normal again, but acknowledging they are not the same as who they were before their diagnosis. They also have to grieve for how their lives might have turned out and who they might have become before they had cancer.

Literature in the area of identity formation and adolescents with cancer has suggested that these young people often struggle to attain the same level of identity formation as their healthy peers (Madan-Swain et al., 2000; Gavaghan & Roach, 1987). Madan-Swain et al. (2000) found that a greater number of cancer survivors were found in the foreclosed identity status when compared to the controls. Individuals who remain at the foreclosed identity status generally do not consider alternative possibilities or viewpoints such as a variety of future job opportunities. Instead, they are more likely to adopt without examination the values and expectations of important adults in their lives such as parents. Participants in the present study all discussed a variety of job possibilities such as in business, social services and health care and did not report that they had been overly limited by parental values and expectations. Many of the young people in this study were very clear about what they wanted from life.

Some participants also described that being a cancer survivor became engrained into their identity and their illness began to define them. Some

examples provided by participants in this study included being labelled the ‘girl with cancer’ or the ‘miracle girl’ by peers. One participant also reported that when seeing a counsellor, the counsellor was unable to look beyond the illness as to what else may be going on to cause her distress. For some participants, having cancer became an integral part of their identity and how others came to view them. In the literature on identity formation, there was not much written about how cancer came to define the individual. However, this finding highlights an important need for those working with young people with cancer not to assume that cancer is the only thing that is going on for the young person. Cancer may simply only be a part of what is impacting them, and it is important to be able to look past the illness. This finding emphasises that participants wanted others to be aware that cancer is an important part of who they are, but it is not the only part of who they are.

#### *Cancer can be a time of personal growth and development*

Literature has suggested that experiencing cancer in adolescence can lead to a variety of adverse psychological, social and behavioural outcomes (e.g. Nathan et al., 2009; Gurney et al., 2009; Upton & Eiser, 2006; Hudson et al., 2003; Mulhern, Merchant, Gajjar, Reddick, & Kum, 2004). However, previous research has also sought to examine whether positive outcomes may emerge from negative life experiences such as cancer (e.g. Novakovic et al., 1996; Hedstrom, Skolin, & von Essen, 2004; Mattsson, Ringner, Ljungman, & von Essen, 2007). Sundberg, Lampic, Bjork, Arvidson, and Wettergren (2009) found that those who have experienced cancer fare the same or even better than matched healthy controls in areas of psychological well being, such as resilience and appreciation for life and relationships.

Within this study, participants were specifically asked if they felt that their illness had resulted in any positive changes to their life. All participants spoke extensively about how having cancer challenged them to think about what was important in their life. Most participants also described that having cancer emphasised that they should be taking advantage of every opportunity they are provided with, as life was not a guaranteed thing. These findings were consistent

with research by Mattsson and colleagues (2007) who found that participants in their qualitative study were able to identify a number of ways in which they felt their lives had been affected in a positive way by having cancer. Some examples included not letting small problems irritate them as they once had and instead focusing on taking advantage of all opportunities, which was very similar to the participants' experiences in the present study.

Positive changes in an individual's identity, goals and values following a traumatic event such as cancer have been labelled post-traumatic growth (Tedeschi, Park and Calhoun, 1998). Being able to reframe an illness in a positive way such as by now appreciating life more and taking every opportunity is well aligned with the concept of post-traumatic growth, as the appreciation for life was described to be currently more now, than they had prior to their diagnosis.

Another concept aligned with the theme of growth and development that emerged from the interviews in the present study included a perceived increase in maturity. Participants described having to grow up faster than their peers as a necessity to understand more about their illness and as a way to be able to effectively communicate with a number of adult professionals. Some participants also commented that their change in perspective and how they viewed the world following their diagnosis also made them feel as though their level of maturity was higher than their peers.

This finding is consistent with several studies such as Mattson et al., (2007) who examined positive outcomes of adolescents who had experienced cancer. In this study, having to grow up and mature faster was a common theme identified by participants. Similarly, in a study by Wicks and Mitchell (2010) in New Zealand of ten adolescents who had cancer, all but one of the participants were able to spontaneously name at least one benefit that resulted from their experience of cancer. One of these perceived benefits included personal changes such as an increase in maturity. In terms of how this maturity affected the participants, some participants described thinking more about how they could give back to others with cancer and provided examples such as helping out with support services. This is consistent with findings by Stegenga and Ward-Smith (2009) who found that many of the adolescents they worked with expressed an altruistic desire to give back. For example, some participants mentioned wanting

to help others who were behind them on the cancer journey, while others were thinking about how their possible career pathways could contribute. Similarly, Mattson et al., (2007) found that the young people in their study commented that the knowledge and experience they gained from learning about their illness, and being involved with health care services encouraged them to widen their perspectives to think about different careers and recreational activities (Mattsson et al., 2007). Participants in this study did not explicitly say that their illness had influenced their interest in certain jobs; however, three participants were considering careers in the area of health, which might have been related to their own experience. Finding out how a cancer diagnosis has affected their choice of occupations and interest in terms of study could be an interesting avenue to explore in further research.

Generally literature has suggested that growth and an increase in maturity is a positive change for young people who have experienced cancer (Mattson et al., 2007). However, it is important to acknowledge that it may also create further challenges for young people, particularly with regards to their peer relationships. For example, differences in maturity levels between the adolescent and their peers may further perpetuate an image of being different from their peers or feelings of disconnectedness and isolation. This is particularly imperative for this age group, where this is an immense pressure to be accepted by their peer group (Conger & Galambos, 1997). This may also make it more challenging for the young person to reconnect with the peers if there is an obvious difference in maturity and what they want out of life and if they cannot understand each other.

Another finding from the present study was that cancer changed goals and priorities. Some of the physical effects of the illness meant that participants in the present study had to relearn basic skills such as walking and feeding themselves. As a result, there was a shift in focus from an interest in the opposite sex and spending time with peers to recovery. Participants described having to evaluate what was most important to them at that point in time, as many participants expressed that what was most important was to be healthy.

This finding also emphasised difficulties participants had when reconnecting with peers, when they felt they now had very different goals. Participants described feelings of frustration and annoyance when their peers

would focus on trivial details in life such as what they would wear, when they had come to believe these things were not as important. One participant commented that it was just easier to associate with older people who did share these same goals, rather than reconnecting with similar aged peers. Differences in goals and priorities could lead to challenges rebuilding relationships or reintegrating back into their social environment. Therefore it may be useful to consider how to encourage young people to openly discuss their change in goals or perspectives with their peers. Furthermore, it would be useful to educate the peers about changes in priorities after a cancer diagnosis and how they can use that information to support their friend.

### *Limitations*

There were a number of limitations of this research that need to be acknowledged and considered. Firstly, only a small number of participants were interviewed for this study. This small sample size was partly due to difficulty recruiting participants for this study. Even with exploring numerous avenues for recruitment, such as working with Canteen, posting advertisements on social media, putting posters up around the tertiary institutions in Hamilton and writing a press release for the local newspaper, I only managed to recruit eight participants. This study aimed to understand experiences about the people that were interviewed; therefore, it is imperative to understand that the experiences are about these people, not all people. For example, there may be differences based on ethnicity, family structure, personality traits, previous exposure to traumatic events, age at diagnosis or where they currently live (e.g. urban vs. rural) that were not expressed by participants that took part in this study.

In addition, it is important to acknowledge that all eight participants that volunteered to take part in this research identified as New Zealand European. While I aimed to recruit young people from a variety of ethnicities, unfortunately there were no participants from other ethnicities. This limits the generalisability of the results to young people from different ethnicities who may have had differing experiences for a variety of reasons such as different cultural beliefs or expectations around illness. To further enhance the understanding of young people's experiences of cancer within a New Zealand context and to more

accurately represent the diverse population in New Zealand, further research with adolescents from other ethnicities could provide useful information about their experience and to explore any cultural differences that may emerge.

Recruiting participants primarily using Canteen could also be seen as a limitation. This meant that potential participants who did not utilise support services were perhaps unaware of the research. Further research would be useful to examine if there are any differences between those who engage in support agencies such as Canteen and those who do not. One way to possibly increase the potential pool of participants could be by working with treatment and health care providers.

I also think it is important to acknowledge that the young people who volunteered for this type of study may be people that are simply more likely than others to share their experience of cancer. Perhaps those who did have a particularly traumatic experience of their illness would be more reluctant to volunteer to talk about this experience in a study of this nature, as it may be too distressing to discuss or they try to avoid talking about it. This has implications when considering the generalisability of this research to a wider population and how representative this sample is of young people who have experienced cancer.

Reflecting on the influence of my role as a researcher, there were a number of factors that may have influenced the way participants responded in the interviews. Being a similar age to the participants may have meant the participants felt more comfortable discussing topics that were relevant to young adulthood as they may have felt that I could relate more with some of these issues. However, there may have been other topics that the young people may have felt more comfortable discussing with someone who perhaps was less likely to relate to some of the experiences. My experience working with Camp Quality may have also influenced some of the participants who may have also been personally involved with the camps. I emphasised that the interview content would be carefully anonymised and the details of the interview would be kept confidential. Reflecting on the interviews, there did not appear to be any process issues that were interfering with the participants' being able to talk freely with me. No concerns about any of the issues mentioned above were expressed by the participants.

### *Recommendations for further research*

The aim of this study was to understand the experiences of adolescents who had cancer. This study has identified further research in this area that would be necessary to both substantiate and extend on the findings of this study.

Suggestions for future research include:

- To capture the experiences of the diverse population in New Zealand, further research with adolescents from other ethnicities and more diverse cultures could provide useful information about their experience and to explore any cultural differences that may emerge. This could be done by aiming to recruit participants from a variety of ethnic and cultural backgrounds.
- Examining the impact of the issues discussed in this study for young people who have had no input from support services such as Canteen. It would be useful to examine where people who do not use support services find their support and what impact this has on their recovery and wellbeing.
- To further explore specific ways a cancer diagnosis has affected future avenues of adolescents' lives. For example, it could be useful to determine if having cancer changed what sort of occupation they wanted to do or changed their interests.
- To also interview parents about the topics identified in this study. Further research could examine parents' perceptions of the adolescents coping strategies, impact on adolescence and the effect on relationships and expectations. This could enhance the findings of this study or identify other areas of need that were not addressed in the current study.
- To further explore the needs of siblings supporting those with cancer. This could identify unmet needs of siblings and could examine what they believe could be useful to know or could help them through their siblings' cancer journey.

*Recommendations for services and agencies working with this population*

Based on the findings on this study a number of recommendations for services, professionals and agencies working within this area have been made. Some of these recommendations include:

- Continuing to support the young person with cancer following completion of their treatment. While they receive medical checkups throughout their recovery to assess any physical issues, it is also imperative that professionals examine whether the young people feel their emotional and psychological needs are being met.
- To offer support and information for siblings and parents of those with cancer. This could be through discussions with the whole family. Education could also be useful so that close family members are more aware of ways they can offer practical and emotional support.
- To offer support and education for peers of those with cancer. As a major finding in this study was that many young people with cancer felt that their peers were not equipped to deal with their illness and often struggled to know what to say, there is a need to help peers of those with cancer through this journey. This education could take place in schools or could be completed with groups of friends wanting to seek more information. It may be useful for peers to have more knowledge about what to expect from their friends' illness and also to be given practical ways they can offer support. It is important to acknowledge that this may include complex confidentiality issues, and would need to be done in collaboration with the youth and family.
- For professionals to consider the appropriate time for the provision of information about a young person's illness and to consider if the information being provided is developmentally appropriate. This study highlighted that the best time to receive information depends on the individual; however, in general receiving information close to the diagnosis period was considered overwhelming for the adolescent. Instead, they started to feel empowered by learning more about their illness in the treatment phase of their illness.
- To provide information and support for young people regarding how their intimate relationships may be impacted by cancer. Young people might

benefit from learning how to comfortably bring up and discuss issues relating to intimate relationships such as fertility with current and future partners. For those in a relationship, talking to both the young person and their partner might be a useful way to inform both parties about what might be expected.

### *Conclusion*

The purpose of this research was to understand the experiences of adolescents who had cancer and to examine the impact of their illness on their social relationships. Further aims of this research were to examine how young people with cancer coped and found support and the impact of having cancer on the developmental tasks of individuation and identity formation. The results from this study were largely consistent with previous studies in New Zealand and overseas. Prior research has found that young people have identified significant changes to relationships following a cancer diagnosis. Some of these changes included increased closeness to certain people and a loss of friendships due to the peers' inability to cope with their friend's illness (Mattson et al., 2007; Palmer et al., 2007). This change in relationships was consistent with the findings from this study which found that there was a perception that the adolescent was vulnerable and weak and therefore were treated differently from their peers and participants reported that they had lost a number of their peers. This study suggested that adolescents with cancer perceived that some of their friends were unable to find ways to communicate with them during their illness and were not able to offer appropriate support. This has implications for ensuring that peers do have avenues to find out more information about what to expect during their friends experience of cancer and how best to support them through that time. The findings from this study emphasise that young people with cancer coped with their illness in a number of different ways, including using humour and distraction as a way to cope. In addition, acceptance of the illness and moving on was also found to be a useful way to adapt to their illness.

The findings in this study highlight the importance of providing information for adolescents at the right time in their cancer journey. This needs to be a time when they are likely to be able to handle the information and not feel

overwhelmed. It is also imperative that the information is at a developmentally appropriate level. While findings in this study suggested that cancer was conceptualised as a time of loss including a loss of identity and a loss of opportunities, all participants were able to identify positive changes as a result of their illness. These changes included a newfound appreciation for life and making the most of opportunities they are provided. These changes are consistent with the concept of post-traumatic growth which has been defined as a personal growth and change in goals, values and identity following an adverse life event (Tedeschi, Park & Calhoun, 1998). Another key finding from this study was that following the completion of treatment, a major challenge for adolescents was to re-invent the self. There was an emphasis on accepting that they would never go back to their life pre-cancer and instead focus on how to adjust to their new identity as a cancer survivor.

Based on the findings from this study and with consideration to previous literature in this area, recommendations were made to ensure that appropriate emotional and psychological support was offered to young people following completion of treatment. Recommendations were also made to ensure that parents, siblings, partners, other close family members and peers were given enough information about what to expect from the cancer journey and that they were also taught ways in which they can help offer support.

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# Teenage Cancer Survivors

An interview study of how cancer affected your life and relationships

I am a graduate student at the University of Waikato interested in finding out what would help young people cope with cancer. This will involve an interview of about 45 minutes. This will be written up in a Masters thesis, in which confidentiality will be preserved.

**If you have experienced cancer and are between the ages of 16-25, I would love to hear from you**

All participants will receive a **\$15** Westfield Voucher as a thank you for their time

**CONTACT: Rebecca Evans**  
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THE UNIVERSITY OF  
**WAIKATO**  
Te Whare Hōwanga o Waikato



## Appendix B – Participant Information Guide

Participant Information Sheet  
University of Waikato  
Psychology Department



Research looking at social support, coping strategies and impact on relationships for adolescents who have experienced cancer.

Thank you for your interest in this study.

### **What is the study about?**

The purpose of this study is:

- ✚ To learn more about how young people like yourself found support during your illness.
- ✚ To learn how living with cancer has impacted your social relationships such as with family, and friends.
- ✚ To find out how young people living with cancer cope with the illness.
- ✚ To find ways in which organisations that serve young people with cancer can improve their services.

An important part of this study is for you to tell your story about how living with cancer has impacted your life.

### **What is involved in the study?**

This study will involve an interview of approximately 45 minutes. Prior to the interview, you are welcome to read over the interview guide which covers some of the questions that will be asked.

I will be asking you about your experience of cancer, the impact on your relationships and your experience of adolescence.

The information that is gathered will be kept confidential. No names or other identifying information will be used in any notes or in the final research.

The interview will be audio recorded and after the interview has been completed, I will type up the conversation that we had. After the interview has been written up, I will contact you to arrange a time to read over the interview if you wish. This will give you an opportunity to correct any mistakes in the interview or make any additional comments. After this, what I have learnt from your and others interviews will be written up and presented as my Masters thesis.

As a thank you for your valued contribution and giving up your time to talk to me you will be given a \$15 Westfield Voucher.

### **Participant Rights**

- ✚ There will be no identifying information in any notes or any piece of written research.
- ✚ You can ask questions at any time.
- ✚ You can choose not to answer a question I have asked.
- ✚ You may stop the interview at any time.
- ✚ You can withdraw from the research if you wish. If you change your mind about participating or have any concerns about what was said in the interview, you can contact me within a week and we can discuss what to do about it.
- ✚ All information in the interview will be kept confidential, unless there is a danger to you or someone else. In this case, I may be required to tell someone, but I tell you if this is the case.
- ✚ You will have the opportunity to read a written copy of the interview. You will be able to make any changes to incorrect information.
- ✚ You may contact me, my supervisors or the convenor of the University of Waikato Research and Ethics Committee (Dr. Nicola Starkey) if you have any concerns or questions about the study.
- ✚ You can request a summary of findings for after the research has been completed.

Thanks again for your time! Any Questions??

## Appendix C- Interview Question Guide

### Interview Questions

Interviews would last approximately 45 minutes

#### Background information (age, demographic information)

- ✚ Tell me about your family – brothers/ sisters?
- ✚ What are your interests?
- ✚ Can you tell me about your illness?
  - How old were you when you were diagnosed?
  - What kind of cancer was it?

#### Information about illness-

- ✚ How did it feel to be told you had cancer?
- ✚ Where did you find out about your illness? Where could you learn more information?
- ✚ Do you think you received enough information?
- ✚ When others ask you about your illness, do you comfortable telling them?

#### Social Impact-

- ✚ How did you tell your friends/ brothers/ sisters that you had cancer?
- ✚ How did they react to hearing the news?
- ✚ Did having cancer change any of your relationships with friends or family? If yes, how did it change?
- ✚ Did your illness affect what you were able to do with your friends?
- ✚ Did having cancer change how people treated you?
- ✚ Have you met many other young people going through cancer or other illnesses? How was that?

#### Adolescence-

- ✚ What does being a teenager mean to you?

- ✚ What have you found hard about being a teenager?
- ✚ In what ways has living with cancer affected your teenage years?
- ✚ Do you think your parents have set more rules or restrictions because of your illness? How has that made you feel?
- ✚ During your illness, what was a typical weekend like for you?
- ✚ What are the most important things in your life right now?

### **Support/Coping Strategies-**

- ✚ During your illness where did you turn for help and support when needed?
- ✚ What sort of support did you receive?
- ✚ How did you manage the stress and challenges of having cancer?
- ✚ What about the challenges of being a teenager in general?
- ✚ Can you give me an example of something you found challenging, and how you coped with the situation?

### **Services –**

- ✚ Have you been involved with any support groups, agencies or services?
- ✚ What was your experience of these organisations?
- ✚ What are the best aspects of organisations and support groups that you have worked with?
- ✚ Is there anything you wish the organisations could do better? Was there anything you needed, that you felt you didn't receive?

### **Impact on other aspects of life-**

- ✚ Do you think your illness has disadvantaged you in any way? Are there any things you cannot do now?
- ✚ Do you think your illness has had a positive impact on your life in anyway?
- ✚ What impact has your illness had on your school work?
- ✚ What ways could people help you with keeping up to date with school?
- ✚ At the present time, how would you rate your health?

- ✚ Do you think having cancer taught you anything that others your age might not have learnt?
- ✚ Is there anything else you would like to say or add?

### Teenage Cancer Survivors: Participants Wanted!

Rebecca Evans is a psychology graduate student currently working on her Masters thesis at the University of Waikato. Her interest in health psychology and working with young people helped to shape this study, as well as a desire to create a piece of research that could give something back to the people involved. The purpose of the research is to look at social support, coping strategies and the impact on relationships for adolescents who have experienced cancer. Rebecca hopes this will provide valuable information about what may help young people and their friends and family to cope with cancer. “I really want to create an open and honest space where these young people can feel comfortable to share their journey with me, where they are able to discuss the impact cancer had on their adolescent years and the effect on their relationships with peers and family”. She hopes to use the knowledge gained from this research to add to the growing New Zealand literature in this area.

Having received approval from the School of Psychology’s Research Ethics committee, Rebecca is now looking for young people aged between 16 and 25, who were diagnosed with cancer between the age of 13 and 20. If you fit this criteria, Rebecca would love to hear from you. Interviews will take approximately one hour, will be confidential and will be held in a comfortable place for the participants. As a thank you for their time and for sharing their experiences, all participants will receive a \$15 Westfield voucher. For more information please contact Rebecca on #####.