The psychosocial interactions of Adolescent and Young Adult (AYA) cancer survivors and the possible relationship with their development

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Abstract

Adolescents and Young Adults (AYAs) with cancer may be particularly affected by social interactions, as they can be grappling with both a serious illness and normal developmental challenges. The present research aims to increase the understanding of the psychosocial interactions of AYAs with cancer and how these interactions can be grouped and organised in relation to each other. Furthermore, this research hopes to examine the relationship that cancer has with the developmental trajectory of this population, and how social interactions influence this relationship. As development is an important aspect of this age group, it is appropriate to consider both psychosocial interactions and the development of AYA survivors.

Qualitative interviews asked ten participants (aged 16-25 years) to describe their psychosocial interactions and examined how these might affect their development. Thematic analysis identified a range of themes including: the importance of personal privacy and controlled sharing of information, independence, identity formation, positivity, acknowledgement of cancer vs. being treated normally, and receiving support instead of supporting others. In the one year follow-up interviews with five participants, half of these themes remained constant; however the personal privacy, independence and supporting others themes changed. Development appeared to be impacted by cancer for both adolescents and young adults, but this impact lessened over a one-year period.

A quantitative study followed, which involved asking thirty AYAs to sort psychosocial interactions using a GOPA card-sort process, resulting in a multidimensional model of interactions. Interactions were derived from a combination of the aforementioned interviews, and a similar model completed for an Honours thesis. This model showed that AYAs conceptualise interactions in two main ways: through their perception of emotional response (avoidance/discomfort interactions opposed support interactions) and empathy (empathic actions/encouragement interactions opposed thoughtlessness interactions). Unfortunately the sample size was too small to complete two separate models comparing age differences, and therefore an understanding of developmental disparities in conceptualising interactions was unable to occur.

Overall, social interactions and developmental stage appear to influence AYAs' experience of cancer. Together, these two studies provide an understanding of how AYAs in New Zealand experience and perceive psychosocial interactions. Furthermore, there is an enhanced understanding of the developmental impact that cancer has on AYAs' interactions. This research proudly contributes to the body of knowledge on AYAs in New Zealand, their psychosocial needs and the way cancer impacts on their development.

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Prologue

"The way that they see their situation is half of the fight … as bad as cancer is in itself, I find that it often brings out the best in people"

- Matthew

As an aspect of qualitative research includes the reflection of the researcher on their position within the research itself, this section serves as an explication of the researcher's positioning in this study.

The topic that this research is set in evokes emotion and sensitivity in many people. Cancer is personal. My history involves cancer, in that I was diagnosed with Hodgkin's Lymphoma at age 14. Thus, for me, cancer was very personal, and was a lived experience throughout my adolescence. Following my diagnosis I found it difficult to digest the far-ranging comments that came from family, friends, acquaintances and strangers on the street. People had advice, recommendations, alternative therapies, stares, concerns and compliments. I found it fascinating to watch the changes in people's faces and demeanor when they were told that I had cancer. Cancer affects people in a way like no other disease, not just physically, but also intrapersonally and interpersonally.

My interest in psychosocial interactions between those with cancer and others is therefore set amongst my personal background. My Honours thesis aimed to create a model that included a comprehensive collection of all possible social interactions. I read many studies for that project that examined the experiences of others with cancer, and I realised the unique nature of the cancer experience for various individuals. It is not the same for everyone, and different people prefer different approaches to managing their illness, and in how others help them to do this. My strong interest however, was the Adolescent and Young Adult (AYA) population with cancer. This was the most pertinent to me and the most personal. These individuals experience so much psychosocial change in addition to their cancer. They are faced with developmental challenges involving identity, control, and individuation issues, as well as peer experiences that are different to any other age group. My focus for this project then became the AYA population and their psychosocial interactions, coupled with the challenges presented by their normal developmental tasks.

As an individual, while I do not identify with any cancer-related group such as CanTeen, I am a person who has had cancer and that experience has contributed to who I am today. As a researcher, it became important to separate who I am as a person and who I am as a researcher, whilst not ignoring the additional knowledge that I have as a cancer survivor. In order to recruit participants from this (thankfully) rather scarce population in New Zealand I needed to approach the likes of CanTeen to introduce myself and this research. I had – and still have – a strong desire to present myself as a researcher who had cancer to the participants in this study. This desire is embedded in an understanding that there are connections between people with similar experiences, especially those experiences that are so emotional and sensitive as cancer. I wanted to allow my participants to feel they could trust me on a level that allowed them to open up to me and share their experiences in a safe and understanding environment. However, I needed to find a position I was comfortable with, for myself and for this research. Consequently, I tried not to share too many of my own experiences or emotions with participants. I needed to keep this private to ensure the professionalism of my role, and to keep the person and the researcher as individual entities.

The experience of having cancer for me has now become so long ago that I can gain some perspective from it; however it is important to recognise that this is not the case for everyone. In part to protect myself and in part to acknowledge the difficulty associated with talking about the cancer experience, I felt it was essential to disclose my history to participants. The purpose of sharing my experience with participants was not to become immersed in similar experiences and the emotional content of these; instead it was to reduce the power imbalance between the researcher and participants, and create that safe and trusted environment.

In saying that, my personal connection to participant's stories, especially those shared throughout the interviews, left me feeling bittersweet. Bitter, because their stories were at times achingly sad; but sweet too, because the perspective that each participant had was incredibly inspiring. They viewed cancer as a speed bump, a triumph and as a contribution to who they are today. They showed strength and resilience that is unparalleled to anything that I have seen or heard of before. They are my biggest inspiration.

This is not my story – it is the story of the generous participants who kindly agreed to share their personal experiences. This is their story, and in sharing this with others, I hope to be a voice for the young people managing their development in the face of cancer, and assist others to be able to help them in positive and empowering ways.

Chapter One

Introduction

Adolescents and Young Adults (AYAs)

The population of particular interest to this research is Adolescent and Young Adult (AYA) cancer survivors, a group of young people who are in the process of transitioning from children to adults. The adversities that are often exclusive to AYAs spread across medical, psychological, and social spectrums, among others. With a lifetime ahead of them, young people can be dealing with issues from facing their own mortality to long-term effects of a serious illness and subsequent treatments. Their experience of cancer may set them up for their approach to their lives post-cancer, both physically and psychologically. Pivotal to their experience is the support they receive from those around them, and the amelioration of psychosocial hurdles.

Like other age groups, cancer in AYAs is the leading cause of non-accidental death among developed countries (Padhye & Gabriel, 2013), indicating the severity of the illness. For this population, some of the main issues for the management of cancer include a delay in diagnosis, the decision to be treated in either a pediatric or adult setting (neither of which is ideal for AYAs), decreased participation in clinical trials compared with adults, poor treatment adherence, psychosocial issues (including unmet social support needs) and fertility preservation (Padhye & Gabriel, 2013). These issues are largely unique to the AYA age group, and distinguish it from the issues present in childhood and adult cancers. To increase survival rates and provide better survivorship care, these issues need to be addressed. Social support is one area where the support network around young people with cancer can be improved. Before discussing the literature on AYAs and their psychosocial needs, it is important to define key terms that are pivotal in this research. The next sections outline the key definitions used in this study – what constitutes an AYA, social support, social and psychosocial interactions - acknowledging the contested nature of some of these constructs.

Defining AYA

The term 'AYA' used in this thesis refers to Adolescent and Young Adult cancer survivors, unless explicitly stated otherwise. The age range for AYAs is interpreted more or less liberally among different countries, with some research separating adolescents (anywhere between 12-19) and young adults (anywhere between 20-39). There is no universally accepted age range that delineates 'AYA'. America tends to favour the upper age range of 39 years for young adults, while Australia largely accepts 15-29 year olds for the AYA population and the United Kingdom refer to teenagers and young adults as those aged 13-24 years. The National Child Cancer Network in New Zealand defines children as 0-14 years, and AYAs as aged between 15-24 years. CanTeen New Zealand, a support agency for young people affected by cancer, includes those aged between 13-24 in their network. All of these age ranges include young people who may have vastly different needs and experiences. Where possible, the age group that individual studies have targeted (for example, adolescents or young adults) is included to provide some indication of the developmental issues relevant to the age group.

Defining social support, psychosocial support and interactions

Social support is a broad and encompassing term with a number of connotations. For instance, there is intended social support (from the sender) and the interpreted social support (from the receiver), where the message conveyed and interpreted may not be what was intended. Shumaker and Brownell (1984) define social support as “an exchange of resources between at least two individuals perceived by the provider or the recipient to be intended to enhance the well-being of the recipient” (p. 13). This definition relies on social support including an aspect of good intention on the provider’s behalf, but it does not account for social interactions where the provider or sender did not have good intentions (for example, making eye contact then looking away). However it does denote the fine balance between the intention of the provider and the interpretation of the recipient, where there is an exchange of resources with the assumption of support. Social support also encompasses emotional, tangible, and informational support, as these offer various components of the exchange of resources mentioned earlier. Social support, for the purposes of this research, is assumed to be favourably interpreted by the receiver unless the literature in question describes an interaction as negative (more discussion of this to follow).

Psychosocial interactions are related to the broad term described above for social support. For the purposes of this research, psychosocial interactions are defined as verbal and non-verbal (ignoring, body actions such as nodding, staring) transactions between the AYA and someone else. These interactions can be social and therefore purposeful, or they may be non-purposeful and have psychological implications for the AYA (such as the effects of feeling ignored or being stared at). Lally et al. (2013) defined unsupportive social interactions as those upsetting and between two people who have some form of social relationship, therefore excluding interactions with strangers.

However, Lally et al. (2013) included both intentional and non-intentional interactions in their definition as interactions were based on how they affected the person with cancer, rather than whether they were purposefully upsetting. Shapiro (1990) noted psychosocial interactions (in the form of doctor and patient interactions) include communication which is sensitive to the recipient’s feelings and thus likely purposeful. Both of these studies together define psychosocial interactions in a way that is consistent with our definition. We define psychosocial support as encompassing both positive and negative psychosocial interactions.

AYAs in New Zealand

The most recent statistics in New Zealand for AYA cancer refer to 2015, where there were 168 new diagnoses in the 16-24 age range (Ballantine & Sullivan, 2013; Bradbeer & Ballantine, 2015; Ministry of Health, 2017). According to the Adolescent and Young Adult Cancer Incidence and Survival in New Zealand report, the most current report prepared for the AYA Advisory Group in 2013, there were 1606 AYAs (aged between 12-24) diagnosed with cancer between 2000-2009 (Ballantine & Sullivan, 2013). Among the most common of those cancers for the 15-24 year age bracket were lymphomas, leukaemias, melanoma, bone tumours, carcinomas and germ cell tumours (Ballantine & Sullivan, 2013). According to the report, between 2000 and 2009 there were on average 160 new cases of cancer in AYA each year in New Zealand.

The overall relative survival rate for AYA cancers averages at 80% five years after diagnosis; however, the survival rate for 20-24 year olds is significantly higher than those aged 15-19 years (Ballantine & Sullivan, 2013). These figures may appear pleasing; however, the overall survival rate for AYA (15-24 years) cancer cases in New Zealand (80%) is substantially lower than the average of the 23 European countries that contributed to the EUROCARE consortium (an average of 87.4%). The New Zealand five year survival rate for 15-19 years of 75% is also lower than that of the United States at 82% and Canada at 81% (Ballantine & Sullivan, 2013). Nonetheless, the 5-year relative survival rate for AYA cases has improved in both adolescent (15-19 years) and young adult (20-24) groups between the 1988-2002 review and the 2000-2009 review (Ballantine & Sullivan, 2013). This suggests that cancer survival rates are gradually increasing for this group in New Zealand. This also implies that more AYA cancer survivors exist in New Zealand than before, with a potential to increase further in the future.

The present study

The present study aimed to increase the understanding of the psychosocial interactions of AYA cancer survivors and how they relate to each other. Furthermore, this research hoped to examine the relationship that cancer has with the developmental trajectory of this population, and how psychosocial interactions influence this relationship. As development is an important aspect of this age group (16-25 year olds), it was appropriate to consider both psychosocial interactions and the development of AYA survivors. Interviews were be conducted with a small sample of the AYA population to: firstly, establish which psychosocial interactions were relevant and applicable to this age group; secondly, discuss these interactions, including asking participants which interactions might be more or less helpful; and thirdly, to explore the effect of cancer on the development of these young people. One-year follow up interviews hoped to provide a longitudinal aspect where changes in both perspectives on psychosocial interactions and the effect on development could be determined. By interviewing the same population sample one year apart, patterns of developmental impact became evident.

The last stage of this study also aimed to apply the psychosocial model of interactions by Cameron (2015) to the AYA population. This required identifying interactions relevant to AYAs from the interviews and combining these with appropriate interactions from the adult model. AYAs were then asked to organise all interactions into similar and opposite groups, to better understand how they perceived the interactions to be related. To establish whether developmental stage affected the way adolescents and young adults sort items, we hoped to create two models to compare age-disparate responses. These models aimed to provide an idea of how development impacted the perception of psychosocial interactions.

This research provided an opportunity to attempt to fill current gaps in knowledge, especially as there has been little research on the AYA population in New Zealand thus far. This was the first attempt that I was aware of to further our understanding of psychosocial interactions and examine the developmental impact of these on AYA cancer survivors in New Zealand. In addition, this aimed to improve our understanding of psychosocial interactions both qualitatively and quantitatively by providing a thorough study of how they affected AYAs, and how AYAs understood these. Considering the developmental impact on this population by reviewing this impact qualitatively at zero- and one-year points gave a unique awareness of how development can change over time, and examining conceptual differences in the quantitative model provided a different angle again on these interactions. Understanding conceptual differences in how adolescents and young adults perceive psychosocial interactions is essential to our knowledge of the developmental differences between these age groups. Therefore, there is value in aiming to understand AYAs' psychosocial interactions from both qualitative and quantitative perspectives. The combined qualitative and quantitative findings should provide an explanation of the psychosocial interactions applicable to AYAs in New Zealand, how young people themselves perceived them, and how were are impacted by developmental factors.

It is believed that a more comprehensive understanding of AYA survivors' psychosocial experiences and developmental impact due to cancer will enable the family, friends and health professionals who interact with this group to continue to enhance the provision of positive support for the individuals involved. It is hoped that eventually these findings will be disseminated through resources that will be available for family, friends and any person who knows a young person with cancer, with the aim of encouraging positive support for these individuals. The models created in this study provide a comprehensive range of interactions and allowed consumers – AYAs – to organise these into groups.

While the overall aim was to examine the psychosocial interactions of AYA survivors and the impact of cancer on their development, this study was split into two smaller studies (interviews and a card-sort task), each with their own objectives:

Interviews

Objectives:

1. To explore helpful or unhelpful interactions and the relationship between experiencing cancer and the development of these young people.
2. The replication of the interviews one-year later aimed to identify if time or age effected AYAs psychosocial interactions, or their perception of these interactions.
3. To explore whether a one-year time period affected the developmental impact on these young people.
4. To identify psychosocial interactions that were relevant to young people (that were not present in the adult model).

Research questions:

1. What psychosocial interactions do AYAs encounter in their experience with cancer?
2. How do these interactions relate to those that are present in the literature?
3. Which interactions are most and least helpful, and why?
4. How do participants believe their development is impacted as a result of experiencing cancer?
5. Does the developmental impact on participants concur with previous findings in the literature?
6. Are there any changes in developmental impact one year on from initial interviews?

Card-sort study

Objectives:

1. To remodel the adult-based model by Cameron (2015), using data from the interviews conducted in the interviews with AYAs combined with interactions identified in the existing model, and apply this to the AYA population. The new model aimed to provide a comprehensive model of interactions that were appropriate to the AYA age group.
2. To compare age responses by creating one adolescent model, and one young adult model. The comparison between the two models should explain how development affected the perception of psychosocial interactions.

Research questions:

1. Which interactions do participants view as similar and opposite?
2. How do individual items group together as clusters?
3. What dimensions are identified in the models?
4. How do the clusters and dimensions relate to what is currently known about psychosocial interactions for AYAs in the literature?
5. Do any gaps or holes exist in the models suggesting unidentified or missing literature?
6. What differences exist between the adolescent and young adult models?

Predictions:

1. It was hypothesised that some clusters would be the same as those identified in the pilot model (Cameron, 2015).
2. It was hypothesised that the dimensions identified in the models would also be the same as those identified in the pilot model, especially the 'Distancing/Avoidance' and 'Support' dimensions (Cameron, 2015).

Thesis Chapter Outline

The following outline describes the chapters that follow this section. They have been written to flow sequentially in the order that each study occurred. **Chapter One** is a background literature review that explores the existing literature in the area of AYA cancer, social support and developmental impacts of cancer. **Chapter Two** discusses the methodological and epistemological positioning that was the foundation for this research. **Chapter Three** features the qualitative interviews and follow-up interviews, which are written as a journal article. It has been accepted for publication by the Cancer Nursing journal. The article focuses solely on the psychosocial interactions of AYAs and the impact on their development. Following this, **Chapter Four** is a connecting chapter, and reflects on the challenges and findings of the interviews. **Chapter Five** is also a connecting chapter discussing the method of the card-sort study. It discusses the rationale for using a mixed methods approach, and explains the GOPA process and analysis used to form the multi-dimensional model. **Chapter Six** details the card-sort task, and is also written as a journal article. This manuscript has been submitted to the Journal of Cancer Survivorship for publication. **Chapter Seven** is another self-reflective chapter that reflects on the challenges and findings of the card-sort study. Finally, **Chapter Eight** is a discussion chapter, summarising the findings from both qualitative and quantitative studies, discussing how the findings of each study influence the other, answering research questions, exploring how the findings relate to the Honours model, and identifying limitations and recommendations for further research. A final conclusion, **Chapter Nine**, ties together the body of the thesis.

Chapter Two

Background Literature

"I will forever live everyday with cancer. And I wouldn't have it any other way."

- Participant account (Leal et al., 2015)

Cancer has a significant impact on many New Zealanders' lives. The New Zealand Cancer Registry, which records the rate of registered cancer diagnoses from 1948, shows a remarkable rise in diagnoses to the most recent available data in 2015 (Ministry of Health, 2018). Total cancer diagnoses in a range of selected cancers rose from a total of 3474 cases in 1948, to a total of 23,215 cases in 2015 (Ministry of Health, 2018). The rate of deaths related to cancer has also gradually risen, with the New Zealand Mortality Collection citing 2522 deaths in 1948 compared with 9615 deaths in 2015 (Ministry of Health, 2018). However, the rate of cancer-related deaths has not followed at the rate of cancer diagnoses, perhaps indicating the increase in technology and treatment options in later years. With more New Zealanders being diagnosed with cancer and fewer dying as a result of cancer, there are more people living post-cancer than ever before.

As discussed in the Introduction, the focus for this research is the Adolescent and Young Adult (AYA) population. Therefore this review discusses the literature on AYA cancer survivors and their development, psychosocial challenges, and the impact of cancer on a young person. Following this is an examination of the broader literature on social support for the general population and lastly, the relationship between social support and the AYAs' experience of cancer is explored.

Adolescents and Young Adults (AYAs)

"Surviving traumatic illness like leukemia at my age made me think I could survive anything. But the getting better part — well, it nearly broke me . . . Getting better brings about its own problems just as much as being sick does and, as I found, these are rarely identified, let alone discussed. And while there are some fantastic positives to be gained from undergoing an ordeal like cancer, if the negatives are never addressed, how can they be overcome? "

- Magazine excerpt, p. 32 (Miles, 2000)

AYAs in New Zealand

Adolescents and young adults are in a unique situation both in their development and within the medical world. They are neither children nor fully developed adults, and consequently, they neither fit entirely within paediatric or adult cancer services. In addition to there being differences in survival rates of AYAs in New Zealand, compared to other countries, and within the age range itself, there are also differences between AYA survival rates and childhood cancer. The 2013 AYA Advisory Group report acknowledged that compared with the increasingly positive outcomes seen in childhood cancer cases, there is a lack of improving outcomes for the AYA population (Ballantine & Sullivan, 2013). As a result of this report, an AYA Cancer Network was established to ensure ongoing service development, continued research on survivorship disparities, and the development of national standards for AYA cancer services (Pettit & Watson, 2016). The AYA Standards of Care were developed by the AYA Cancer Network and supported by the Ministry of Health. According to the overview on the Standards of Care webpage, their goal is to "achieve excellence in AYA cancer care and address outcome disparities for certain ethnic, disease specific and age related populations for and among AYA in New Zealand" (AYA Cancer Network, 2017). The Standards are divided into three categories: the AYA cancer trajectory, developmentally appropriate care, and institutional support (Pettit & Watson, 2016). It is especially important to consider the developmental challenges facing young people in addition to their experience with cancer.

For many there are huge changes in their lives after a cancer diagnosis. This is particularly true for adolescents and young adults, who may be navigating school, work or other educational opportunities, plus typical developmental challenges that come with this age group. Such challenges relate to forming an identity, relating to peers, becoming increasingly independent and less reliant on parents, and deciding where the future will take them (Drew, 2007; Gibbs, 2002; Hilton, Emslie, Hunt, Chapple, & Ziebland, 2009). The friends and peer group of the AYA patient also may not have the skills and knowledge to cope with adequately supporting their friend (Wakefield, McLoone, Butow, Lenthen, & Cohn, 2013). This is why AYAs can benefit from meeting other young people who are also experiencing, or have experienced, cancer as they can provide peer-to-peer support in a knowledgeable and relatable environment (Goldfarb & Casillas, 2014; Thompson, Palmer, & Dyson, 2009). Key developmental theories for this population include Erikson's 8-stage model of psychosocial development, individuation theory and transitioning from adolescent to young adult by a parents' blessing. A fundamental process for all young people is their identity formation, and this is especially impacted by the notion of 'patient' and 'survivor' identities.

Developmental theories

Before delving into the connection between the developmental life stages and AYA cancer survivors, it is helpful to review the developmental theories of most relevance in current literature. Figure 1 displays the common developmental considerations of the adolescent and young adult population, without considering cancer. It shows the extensive issues that this age group deals with, and begins to illustrate that the impact that cancer has on the lives of AYAs is compounded with typical developmental considerations and needs.

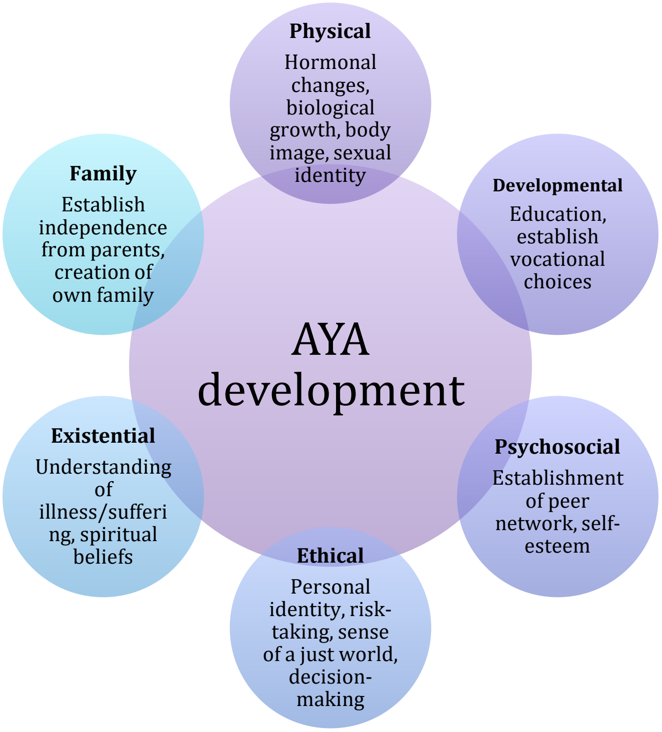

Figure 1. Adolescent and Young Adult (AYA) developmental considerations. Adapted from Wiener, Weaver, Bell, and Sansom-Daly (2015).

Erikson's theory of psychosocial development

Erik Erikson theorized that there are 8 stages of psychosocial development for humans across the lifespan, two of which covered the adolescent and young adult age range. Erikson believed that the adolescence psychosocial stage encompassed the theme of fidelity, where individuals are conflicted between identity vs. confusion, whereas the young adulthood stage emphasised love, with a conflict between intimacy vs. isolation (Kivnick & Wells, 2014). According to Erikson, in adolescence the individual's sense of identity is shaped by personal commitments, beliefs and attitudes, and the activities and relationships that are reflected in these beliefs (Erikson, Erikson, & Kivnick, 1986). These commitments consist of an individual making assurances to both themselves and to others, where the adolescent becomes an entity in themselves and is no longer inherently answerable to only their parents. Young adults require the balance between acknowledging their capacity for love alongside a need for some isolation. Erikson saw the need for isolation as helping the individual realise that they could experience mutual love for another person (Erikson et al., 1986). This is the time for individuals to consider sharing their goals, successes and disappointments with another person, and a time when maturity, in preparation for adulthood, begins to increase.

Erikson viewed the adolescence and young adult periods as highly significant in a person's life; not only as this is the time when both the past and the future are tied together, but also when the individual experiences identity confusion, eventually reaching a crisis (Erikson, 1970a). Erikson (1970a) describes the identity crisis inherent in this youthful age as a time when the individual outgrows childhood and meets the actuality of the world, where he or she is faced with questions both inward about themselves and outward towards the world. Erikson saw adolescence as entailing the gradual learning of morality and ethical thinking, and the desperate attempts to re-experience childhood through what Erikson terms, the 'wholeness of experience' (Erikson, 1970b). Furthermore, Erikson viewed adolescence as the incorporation of fidelity and infantile trust, resulting in a 'malfunction of the will', impulsivity and totalisation (Erikson, 1970b). Thus, the adolescent and young adulthood periods are perceived as somewhat volatile and experiential times, where young people are discovering who they are as well as the world around them.

Rationale for using Erikson's developmental theory

As noted earlier, Erikson coined the term 'identify crisis', which - consistent with cancer research - often occurs as a result of cancer and irrespective of age. This theory aligns well with AYA cancer research, as Erikson understands the substantial effects of the identity formation on young people. The AYA population appears to be impacted by two identity crises around the same time – related to their developmental stage, and as a result of experiencing cancer – particularly negotiating the cancer identity and the survivor identity transition (Jones, Parker-Raley, & Barczyk, 2011). Furthermore Erikson's stages actually align well with international and New Zealand definitions of the AYA age range, since he considers adolescence as ages 13-19, and early adulthood between 20-39 years. Although there are difficulties with comparing studies using different definitions of AYA, Erikson's psychosocial development theory is consistent with all definitions.

Other developmental theories

Various other developmental theories exist that strive to explain the differences in adolescent and young adult ages from those of children and adults. Individuation theory, which predicts that adolescents and young adults develop autonomy by maintaining a healthy relationship with their parents, is a theory extended from attachment theory (Masche, 2008; Smollar & Youniss, 1989). A study by Masche (2008) found support for individuation theory through findings that developmental transitions that occur around the adolescent and young adult timeframe result in closer relationships with parents where high trust levels already exist, especially once they move in with a romantic partner or begin their own family. That is, autonomy during these transitions results in a closer relationship with parents where there are frequent parent-child discussions and high levels of trust (Masche, 2008). This occurs when children begin to view parents less as means-providers and more as a trusted confidant, which is also a movement that can occur when adolescents and young adults are diagnosed with cancer. Masche (2008) findings highlight the complexity of individuation and support for the AYA population.

In addition, some researchers believe that the transition from adolescence to early adulthood pertains to a transformation of sorts within the parent-child relationship, where a blessing from the same sex parent acknowledges the completion of transitioning from adolescence to adulthood (Bjornsen, 2000; Blos, 1985). Blos (1985) believed the blessing was most important for the father-son relationship. Bjornsen (2000) found evidence supporting the value of the blessing, which is to informally acknowledge the adult identity that the late adolescent has grown into. Hence the successful transition from adolescence to adulthood, or young adulthood, may rely on the nature of the relationship between the child and their parents and the parent's support of their child's transition.

AYAs and development

As discussed, numerous developmental theories describe the evolving period that is adolescence and young adulthood. Combining this already turbulent time with experiencing cancer can be very overwhelming for young people. The following section outlines the unique developmental issues affecting AYA cancer survivors, including the identity confusion that may arise for some young people.

Unique developmental issues for AYAs

According to McGoldrick et al. (2011), what distinguishes adolescents and young adults developmentally from other age groups is their perceived invulnerability and an increasing desire to be autonomous. Feelings of invincibility and other developmental cognitive processes can cause a delay in diagnoses as young people present with more advanced cancer (Bleyer, 2007; McGoldrick et al., 2011; Zebrack et al., 2014). Furthermore, symptoms that can mimic developmental changes (for instance, growing pains) can contribute to this delay, as can the need for adolescents to access their family doctor, when they may want privacy from their parents knowing about health problems.

A formative study on the psychosocial effects of cancer on young adults looked specifically at the effect on development and intimacy in relation to Erikson's psychosocial theory of development (Gibbs, 2002). This research involved interviewing 11 survivors of Hodgkin's Lymphoma (aged 25-31 years, who were at least 3 years post-treatment) and 11 controls (aged 25-37 years) to compare for coded themes based on Erikson's psychosocial stages of development. Three major themes emerged from the cancer survivor's group: emotional responses to having experienced a life-threatening illness, the comparison between survivors and controls in relation to trust and identity, and the survivors' relationships and concerns around fertility and having children. In relation to the emotional responses, some participants reported concerns about their health whilst some experienced delayed emotional reactions to having had cancer. Most participants (nine from the eleven in the survivors' group) also reported a loss of trust in their future due to possible relapse, secondary cancer or death.

In terms of identity, participants in this study appeared to be incorporating cancer survivorship into their personal identity. Some survivors struggled to find the right place for cancer within their identities and their lives – including this experience without letting it become 'who they are' as people. Numerous participants struggled with their autonomy, particularly those who felt they had lost autonomy in the cancer treatment process. For a number of survivors, they felt their identities had been altered so much throughout the cancer process that they felt distinctly different from their peers. This included feeling much older than their biological age, both physically and in terms of developmental stages. In particular, facing thoughts about death and dying clashed significantly with the 'normal' developmental experiences of peers.

While most participants reported having supportive relationships with family, spouses or friends, some acknowledged that cancer had caused a strain in relationships and had affected intimacy with spouses. Many survivors felt a sense of limited time and some rushed to make the most of it, either by getting married or having children sooner than otherwise expected. The feeling of urgency caused some survivors to re-assess their lives, and for some that meant ending relationships that were not working and for others it meant living with the idea that time could not be wasted. Intimacy concerns for those without spouses included fears of rejection or embarrassment. Furthermore, family and friends reportedly had difficulty understanding the emotional processes accompanying cancer. However, while some participants experienced difficulties in their relationships due to cancer, others expressed the importance of their spouses' understanding the significance of their cancer experience in their past and present life.

Overall findings in the study showed that cancer survivors were involved more with earlier developmental conflicts such as trust and autonomy, than identity and intimacy (Gibbs, 2002), and this was supported by the findings of Williams, McCarthy, Eyles, and Drew (2013). Gibbs (2002) hypothesised that this could occur because cancer can threaten an individual's fundamental understanding of the world, which results in the undercutting of the earlier developmental challenges that they may have already progressed through. This study highlights the multiple challenges facing survivors of young adult cancer, and the ongoing issues that cancer presents. For those who are even younger when they are diagnosed with cancer, such as in adolescence, these same challenges occur but some present in slightly variant ways.

Survivor identity

Identity formation is part of a key developmental phase for adolescents (Kivnick & Wells, 2014). This process has been shown to be more challenging for AYA survivors due to the conflict between the cancer identity and the survivor identity (Jones et al., 2011), without acknowledging the usual identity exploration that occurs in the teenage to early adult years. The complexities of potentially dealing with not only one but two identity 'crises' in the adolescent and young adult years is something that is being increasingly explored in the literature.

To add another layer to the complex identity issues surrounding AYAs, there are debates about the correct term used to refer to people who have or have had cancer. The use of terms such as 'cancer patient', 'cancer survivor' and 'person with cancer' each have attached to them their own connotations and stereotyped ideas. As Zebrack (2000) explains, cancer survivorship is "the state or process of living after a diagnosis of cancer, regardless of how long a person lives” (p. 239). The term ‘cancer survivor’ is being favoured increasingly in research literature, as it acknowledges that cancer affects an individual’s self-identity (within themselves and from an outsider’s perspective) but it moves away from the sick role ideal associated with the term ‘cancer patient’ (Zebrack, 2000). The ‘cancer patient’ identity can portray individuals as sicker than they perceive themselves to be, can be associated with physical signs like hospital gowns and baldness, and can suggest the person is a hospital inpatient when many individuals are treated as outpatients.

However, the term ‘survivor’ means to come through something, to survive. Some AYA survivors feel they are in between the ‘patient’ and ‘survivor’ identities, where they continue to experience physical, psychological or social effects of cancer which hinders their transition to the survivor identity (Cantrell & Conte, 2009; Lewis, Jordens, Mooney-Somers, Smith, & Kerridge, 2013). Research has suggested that AYAs who hold self-perceived negative stereotypes about cancer survivors may be at higher risk of depression, whereas those who hold self-perceived positive stereotypes about cancer survivors are more likely to have increased survivor self-efficacy (Song et al., 2012). Thus, the individual’s self-perception of what a cancer survivor means can have implications on their psychological well-being.

A study of Latino adolescent cancer survivors found that most participants did not identify with the term “survivor” (Phillips & Jones, 2014), whilst another study found that participants could identify with both a cancer identity and a survivor identity, creating an identity paradox (Jones et al., 2011). The latter study found that the factors contributing to the cancer identity included the lingering physical reminders of treatment and the social isolation following cancer, whilst the survivor identity included worries regarding relapse. These factors resulted in a state of limbo for some participants who had difficulty knowing who they were without cancer. As Jones et al. (2011) explain, this is especially difficult for an age group that are developmentally establishing their own identity and forming peer relationships anyway. From these findings, it appears that terminology preferences are based on each individual and their unique experiences and interpretations.

Physical identity

The physical changes in the bodies of AYAs can cause enough change to make the individual feel that they do not know their body anymore – or at least, their body does not feel like their own. Drew (2007) found that a substantial proportion of AYA survivors in her study had a very negative body image or self-concept. This related to changes in weight, hair loss, physical deformities or surgical scars. Such feelings are further complicated by the contrasting, highly prolific images of men and women (although especially women) in the media, who typify 'perfection' and the supposedly ideal female body (Drew, 2007). Drew (2007) noted that an element of dissociation occurred for some participants, while many female participants who had lost their hair felt that their connection to the feminine identity had been somewhat broken. In addition to this, Carlsson, Kihlgren, and Sorlie (2008) describe the confrontation that adolescent girls face when their bodies and futures change before them as a clear form of suffering. For the adolescent and young adult population, whose personal view of themselves is continually evolving, this can be particularly difficult.

Development markedly influences the cancer experience for AYAs by adding particular questions surrounding their identity, physical appearance, and intimacy. While these questions can consume all young people, those who also experience cancer can find their perception of themselves and their worldview is challenged. However, there is more to the cancer experience than just developmental issues. Cancer affects AYAs in many complex ways, especially into survivorship, which is discussed in the following section.

How cancer affects AYA survivors

"I spent five years of my life being treated for cancer, but since then I've spent fifteen years being treated for things other than looking different from everyone else. It was the pain from that, from feeling ugly, that I always viewed as the great tragedy of my life."

- Lucy Grealy, Autobiography of a Face

The impact cancer has on young people can be widespread. This section outlines the difficulties transitioning from patient to survivor, unmet needs, posttraumatic effects and the positive impact that cancer can leave, too.

Transitioning and unmet needs

There are clear links between levels of distress and unmet needs for AYAs (Dyson, Thompson, Palmer, Thomas, & Schofield, 2012), and both impact on the overall, fundamental cancer experience for individuals. As previously discussed, an increasing number of studies show that the psychosocial issues facing AYA survivors are unique to this age group, separating them from those present in childhood or adult cancer survivors (D'Agostino & Edelstein, 2013; Richter et al., 2015). Increasingly, researchers and medical professionals have focused on the need to develop a better understanding of the survivorship issues facing AYA survivors. Issues related to survivorship and ongoing care are now understood to be a fundamental aspect of good cancer management for AYAs (Anazodo & Chard, 2013), and is likely to be the focus for future researchers in this domain.

There are a number of psychosocial issues that uniquely affect the AYA population. Types of unmet needs for AYA survivors have been identified as long-term survivorship care, fertility issues such as preservation, and mental health well-being and care (Quinn, Goncalves, Sehovic, Bowman, & Reed, 2015). These issues range from lack of information regarding topics such as the effect of cancer on fertility, body image and relationships, to the delivery of services that address survivorship care and mental health needs. These particular unmet needs also make the transition to survivorship care much more difficult, as it is this period where AYAs begin to realise the extent to which cancer will affect their lives. For example, concerns regarding fertility have been linked to depression in young (18-35 year old) female cancer survivors, emphasizing how important it is for unmet needs to be addressed (Gorman, Su, Roberts, Dominick, & Malcarne, 2015). Literature has also identified the substantial impact that cancer can have on AYAs' educational and vocational participation, and the financial implications that may occur both during and after treatment (Fardell et al., 2018).

The idea that there is a prominent discrepancy between the psychosocial needs of AYA survivors and the fulfillment of those needs is now well known. Drew (2007) completed a qualitative study on the experiences of long-term AYA survivors and identified the clear need for acknowledgement and action to address the effects of cancer and its' treatment on the patient that go well beyond the physical ailments. This study, involving members of the Australian CanTeen service, highlighted the experience of survivors who – some between ten to twenty years after treatment – felt the disconnection between their 'selves' and their bodies, and the ongoing compromises they make as a result of cancer. These compromises include a distinction between the AYA survivor and 'normal' people, ongoing physical impairments from treatment such as hair loss or weight management troubles, and the lingering effect that cancer had on identity, where the author stated that survival involves "continually revisiting the history of serious illness in order to make sense of past, current and possible future biopsychosocial consequences of cancer and its treatment" (Drew, 2007, p. 284).

A study comparing 1100 AYA and older patients with thyroid cancer found that both age groups wanted more information and support; however, the AYA group reported having less of these needs met than the older group (Goldfarb & Casillas, 2014). AYA participants in this group were less than half as satisfied with the care given to their concerns regarding medical issues, psychological and practical matters than the over 40-years group. As Goldfarb and Casillas (2014) point out, the

AYA group are perhaps most in need of information regarding long-term effects but are the least likely to get it, despite most living a large portion of their lives in survivorship. Furthermore, research has suggested that for AYA cancer survivors, unmet service needs is strongly linked to lower health-related quality of life (Smith et al., 2013). DeRouen et al. (2015) showed that the greater unmet information need was associated with reduced levels of overall mental and physical health, alongside an association with lower health-related quality of life. The unmet need for information is also likely to impact on other areas of the individual's life, including relationships with others (DeRouen et al., 2015). Thus, research strongly suggests that unmet needs may adversely impact a young person's experience with cancer and could lead to psychological distress.

Posttraumatic effects

A study of the prevalence and predictors of posttraumatic stress symptoms (PTSS) and PTSD in AYA survivors demonstrated that almost half of participants reported moderate or high levels of PTSS one year post-diagnosis compared to one month post-diagnosis (Kwak et al., 2013). Furthermore, at 12 month follow up, 29% of AYAs were at increased risk of PTSD compared with their peers, according to DSM-IV criteria and psychometric assessment. However, it is important to note that the age range for participants was between 14 and 39 years, a much larger range than what is considered to be AYA in New Zealand. The ages of participants were split into three groups, with the 30-39 age group meeting the highest number of diagnoses for PTSD, suggesting the severity of trauma is more apparent in adult survivors than AYAs (Kwak et al., 2013). The authors partly attributed such a high level of PTSS in AYA patients to the compounded issue of dealing with normal developmental challenges alongside those presented by cancer. These findings suggest that health professionals should be carefully monitoring AYAs with cancer for PTSS symptoms, given the stress caused by developmental challenges for this population.

Whilst many health professionals avoid attributing reasonable reactions to major life challenges as clinically severe, studies such as these highlight the considerable effects such an experience can have on AYA patients and survivors, even long after treatment has ended. And while not every AYA survivor will experience PTSS or PTSD, it is reasonable to assume that many AYAs will require some help to learn how to cope with the cancer experience and all that it entails (Haase & Phillips, 2004).

Positive consequences

Whilst there may be a number of negative effects on an individual throughout the cancer experience, studies have also demonstrated some positive psychological outcomes. Zebrack et al. (2015) identified a link between re-experiencing a posttraumatic stress symptom and some aspects of posttraumatic growth. This suggests that while re-experiencing an aspect of the cancer treatment or experience can be stressful, it may also represent a cognitive process that enables AYA cancer survivors to achieve personal growth. The authors noted the vast emphasis in the literature on the negative impacts that cancer can have on an individual, and in contrast pointed to the ways that individuals can psychologically adapt to this experience. Zebrack et al. (2015) report that their findings are consistent with the theoretical perspective that an individual is required to perceive a situation as traumatic to identify experiencing posttraumatic growth. Such growth may perhaps contribute to a sense of meaning from the cancer experience, alongside a sense of purpose for the individual and direction for the future.

Jones, Parker-Raley and Barczyk (2011) found that some AYA survivors reported personal growth since having cancer, enabling them to make meaning from the experience, self-reflect and change who they are for the better. The 12 participants in this study aged between 12 and 20 years who were all post-treatment, each responded that cancer had affected their lives, which had required them to think about what cancer meant to their 'growing selves', especially in the face of the death of fellow AYA patients (Jones et al., 2011). Alongside this meaning was an appreciation for their lives and those important to them. The enormous value of family members who offered support was mentioned by all participants, with one 19-year-old stating, “They didn’t have to say anything. I just knew that they were there, and I could talk to them whenever I wanted” (Jones et al., 2011).

Some AYA survivors identify themselves as stronger and more empowered despite feeling vulnerable to the disease (Zebrack et al., 2014), or that in some way their lives had changed for the better (Phillips & Jones, 2014). This feeling of purpose and reevaluation of one’s life, their values and goals is a common theme among survivors (Zebrack et al., 2014). Such insight into their experience and ability to look at the positives of such a journey is a powerful perspective for AYAs to have, and ultimately allows them to meaningfully interpret their experience.

In summary, cancer affects AYAs in a number of ways, and it can have both positive and negative effects. Positive effects such as posttraumatic growth demonstrate the resilience that young people can build as a result of their experience. On the other hand, negative effects include unmet needs such as survivorship care and fertility issues. Social support can reduce the likelihood of negative impacts in the short and long term, and provides physical and psychological benefits to young people.

Social support

The psychological effect of cancer can be described as a balance of the stress and burden placed on the individual, and the resources that the individual has to cope with these (Andrykowski, Lykins, & Floyd, 2008). The individual’s levels of both stress and burden, and resources are influenced by a number of factors. These include social support, information provided by medical personnel, financial and psychological issues (Andrykowski et al., 2008). Social support can help an individual adapt to news of a cancer diagnosis and the implications that accompany it; however, social interactions that are perceived negatively by the person with cancer can prove to be a burden, by contributing to their stress and reducing social resources. As defined in the Introduction chapter, for the purposes of this research, social interactions include both positive and negative interactions between AYAs and others. Therefore, it is important to equally examine the positive and negative social support and the consequences of each for individuals affected by cancer.

Effects of helpful social support

Social support plays a mediating role in both psychological and physical wellbeing. It has been shown to reduce distress, lead to higher levels of psychological adjustment and self-efficacy, alongside medical benefits such as increased resistance to infection and disease, lower mortality and improved recovery (Blanchard, Albrecht, Ruckdeschel, Grant, & Hemmick, 1995; Dukes Holland & Holahan, 2003). For example, a systematic review has shown that breast cancer progression is negatively correlated with social support, and those with any type of cancer who are emotionally vulnerable and have little social support are at increased risk of tumour growth (Nausheen, Gidron, Peveler, & Moss-Morris, 2009). Similarly, Lehto, Ojanen, and Kellokumpu-Lehtinen (2005) examined social support in terms of quality of life in those with cancer, and found that psychosocial factors influenced stress and quality of life more so than cancer type or treatment. Social support has also been shown to facilitate emotional expression (Wills & O'Carroll Bantum, 2012), which in turn may assist an individual's support networks with offering adequate and appropriate support.

A Finnish study of social support after recent diagnosis showed that in the early stages of crises, contact with just one other person who knew of the diagnosis was enough to elicit feelings of social support (Lehto-Jarnstedt, Ojanen, & Kellokumpu-Lehtinen, 2004). A later study by the same authors found that social support can increase a person's quality of life throughout the cancer experience; however, those who are more socially skilled may see social relationships as more beneficial than others (Lehto et al., 2005). These two studies reinforce the importance of social support for an individual with cancer – regardless of the number of supporters –

suggesting that any amount of social support can be beneficial for that person and their experience.

A Polish study comparing perceived social support between a group of women with cardiac disease, and a group of women with breast cancer, reported that in the latter group, support from a peer support group (Women After Mastectomy Club) appeared to be more effective than support from the women's immediate environment (Malicka, Kozlowska, Wozniewski, Rymaszewska, & Szczepanska-Gieracha, 2016). This implies the power of relating to other people in similar situations, and the level of understanding that is offered in such a group.

Effects of unhelpful social support

While in many instances social support is helpful, there are times when it fails to meet the expectations of the recipient. Research with a group of men with prostate cancer discovered that participants reported a lack of satisfaction with their perceived social support (Paterson, Jones, Rattray, Lauder, & Nabi, 2016). Whilst most reported benefits, some participants experienced higher negative affect as a result of social support (Paterson et al., 2016). Negative affect may have arisen because the person offered the incorrect type of social support, meaning the support offered did not meet those participants' needs. This illustrates the importance of communication between the person with cancer and their support network, to ensure that support is likely to meet the needs of the individual.

Unfortunately, negative beliefs about cancer can lead to negative social interactions. An individuals family and friends' feelings about cancer can be affected by negative beliefs towards cancer and those with cancer, including ideas that cancer is a death sentence, that cancer 'patients' are bed-ridden and terribly ill, and that there are significant adverse effects of treatments (Simon, Wardle, & Miles, 2011). Negative beliefs, or stigma, can be increased where an individuals physical appearance is affected by cancer, such as with some head and neck cancers (and subsequent disfigurement) and hair loss due to chemotherapy (Bonanno & Esmaeli, 2012).

Consequences of such beliefs evident in the family and friends of the individual include excessive fear and dread, which can lead to overprotectiveness (which may be intended to support but is not perceived as support) and avoidance or discomfort behaviours (which are not intended to support or perceived as support), and can cause the person with cancer to perceive less support (Flanagan & Holmes, 2000). Interactions such as the avoidance or discomfort behaviours described by Flanagan and Holmes (2000) are simply social interactions (and not social support), as there is no intention to support the person with cancer.

Support in close relationships

A study by Meyerowitz, Levin, and Harvey (1997) found that post-diagnosis, people with cancer experienced changes in both close and superficial relationships, with some individuals noting decreased closeness or overbearing concern. Decreased closeness involved reduced intimacy, physical avoidance and emotional withdrawal, whereas overly solicitous concern led to some participants feeling isolated and unwilling to spend time around over-concerned people (Meyerowitz et al., 1997). The authors found that many participants believed that only other people who have had cancer would understand the experience, something that many family and friends may not relate to (Meyerowitz et al., 1997).

Individuals have also reported noticing negative changes in their relationships with family. Vrontaras (2018) identified that families can react negatively to the side effects of treatment or surgical outcomes (such as physical appearances), and deny or avoid cancer. The cancer diagnosis also led to a reduction in communication within the families of some participants. Participants in the study also described family support as most useful when expressed as emotional support (in the way of being reassuring, affectionate, expressing interest, or distracting the person from cancer), or practical support, such as visiting in hospital, accompanying the individual to appointments, and assisting with household chores (Vrontaras, 2018).

The obligations and expectations of close relatives and spouses can lead to increased social support or conversely, disappointment, with a study by Gurowka and Lightman (1995) finding that family members provided the most unhelpful responses for people with cancer. Contrary to Lehto-Jarnstedt et al. (2004) findings (that even a small amount of social support can be useful), this study found that despite many actions by family members with good intentions, what distinguished unhelpful from helpful behaviours was the lack of understanding, particularly in regards to the disease, treatment and subsequent effects. Behaviours that do not treat individuals as special cases, and those that emphasise normalcy are named as helpful, as these suggest that despite changes in physical appearance, social and familial relationships remain the same. Both the emphasis on the individual with cancer's current situation and those which dwell on the negative consequences of the situation suggest that the individual is not already aware of the seriousness of the situation, and encourage negative thoughts related to the disease on behalf of the individual affected (Gurowka & Lightman, 1995).

Forsythe et al. (2014) reported that cancer survivors who were not married, had fewer financial resources and reported poor health status had lower levels of perceived tangible and emotional/informational support. These findings suggest that being married or living as married can increase perceived levels of social support. This study also highlighted that marital status had more influence on attendance in follow-up care than perceived social support, indicating the significant role of spouses in survivors' support networks after cancer (Forsythe et al., 2014). Thus it is important to consider the role of the person with cancer's support network when considering their social support needs and survivorship plan. It is useful to consider unsupportive interactions as well as those identified as beneficial, as examining both of these can assist the support network with providing valuable social support.

Types of unsupportive interactions

A study examining unsupportive social interactions immediately after diagnosis among women with breast cancer found that soon after diagnosis, three types of unsupportive interactions were most common – smothering, under or over-sharing of information, and reacting with intense emotion – presumably because the initial news of diagnosis can be a shock and there may be an overwhelming desire to protect the individual (Lally et al., 2013). Age was also a factor in the number of unsupportive interactions women experienced, with "bumbling" (awkward, uncomfortable or inappropriate behaviours), blame, and intense emotion reported more frequently in women aged 50 and under.

Lally et al. (2013) also identified that certain types of interactions were more common with close family and friends than acquaintances. Acquaintances were more likely to react with intense emotion (than family or friends), and make minimising comments (than family members), but were less likely to smother participants than family and friends. Certain interactions were also found to be more common at different stages in the cancer experience than others. For example, bumbling, minimizing, distancing and blaming were more common very soon after diagnosis than after a long period post-diagnosis (Lally et al., 2013). Research with the AYA population has also looked at responses at various stages. For instance, it has been shown that AYAs who have had positive responses during self-disclosure in the past are more likely to self-disclose their diagnosis in the future (Rabin, 2019). This finding supports the significant flow-on effects that supportive social interactions can have.

However, it should be noted that interactions, whether they are classed as supportive or unsupportive, are subjectively categorised. Hilton et al. (2009) found that some young male adults reported being offered sympathy was unsupportive, and instead preferred to incorporate humour into a cancer-related discussion. The authors attributed this preference for humour to being related to retaining a masculine identity, given societal perceptions of men who typically do not discuss feelings or express emotions (Hilton et al., 2009). Therefore, the notion of which interactions are unsupportive or otherwise should be interpreted with caution, and may be influenced by gender constructs.

In summary, social support plays a vital role in the lives of those who experience cancer. While positive support is important for physical and psychological wellbeing, negative social support can cause additional upset and distress. Identifying the most beneficial ways to support those with cancer may help to guide others who are simply unsure of what to do or what to say. Adolescents and Young Adults (AYAs) are one group who are particularly affected by the psychosocial effects of cancer, as they are concurrently experiencing developmental challenges that impact on both their sense of identity, and their interpersonal relationships.

Social support for AYAs

The role of social support for young people

Social support for AYA survivors plays a vital role in the well-being of these young people. Corey, Haase, Azzouz & Monahan (2008) found that perceived social support from friends, family and medical professionals can protect the mental health of AYAs. Perceived social support may also moderate the effects of cancer on AYAs psychological adjustment (Teall, Barrera, Barr, Silva, & Greenberg, 2013), and has proven to be particularly valuable soon after diagnosis (Hexdall & Huebner, 2008). Wesley, Zelikovsky, and Schwartz (2013) proposed a moderation model suggesting that perceived social support for adolescents with cancer moderated the relationship between physical symptoms and affect, with the study suggesting that perceived social support from friends led to positive, but not negative, affect. The individual’s family, friends and peers are obviously instrumental in the social support of AYAs; however, health professionals such as nurses can also play a vital role in the encouragement of social support from the family and friends of AYAs (Olsen & Harder, 2011).

Contrary to the moderation model, some studies show that AYAs are receiving social support with both positive and negative effects. A study by Zebrack, Chesler, and Kaplan (2010) looked at communications and behaviours that were helpful and hurtful/harmful for the physical and emotional well-being of young people. Of the social support behaviours, AYAs considered 'positive attention', 'the promotion of normal life' and 'other survivors' as helpful, and 'negative or lack of attention', and 'denying or dismissing experience' as unhelpful. Positive attention included gifts and visits from others and showed that people cared or were present. Time with other AYA survivors was helpful because of their shared experience. Participants noted that negative attention included inappropriate comments, laughter, ignorance or avoidance, over-protective parents or being made to feel uncomfortable by mental health professionals. Such unhelpful behaviours represent a negative interpretation of the term 'social support' as it is earlier defined, because the intention of the other person is ambiguous, and the behaviour is received by the AYA negatively. Overall the AYA participants stated the importance of interpersonal support and the power of actions and words, suggesting that social support – and negative behaviours – can significantly impact their experience with cancer (Zebrack et al., 2010).

Research by Iannarino, Scott, and Shaunfield (2017) also found that young adults rated being treated as the person they were before cancer was an effective form of support, whereas pity, negative stories about other people who had experienced cancer (such as grandparents), rude remarks, and people who appeared to offer false support (as an attempt to relieve their own sense of guilt or garner attention), were rated ineffective support types. Young adults in this study reported instrumental support (offering to fulfill helpful tasks), and relational support (spending time with the young person) were also effective forms of support (Iannarino et al., 2017).

Family

Studies have shown that support from parents and family, as well as peers, are the most important sources of social support, particularly as adolescents with cancer often live with at least one other family member (Decker, 2007). Because of this cohabitation, family are often considered the main source of support, both practically and emotionally (Wakefield et al., 2013). Research has shown that cancer can have a positive effect on relationships with AYA's parents and siblings (Bellizzi et al., 2012) and can increase their appreciation for their family's support (Lehmann et al., 2014); however, this is also likely to depend on the familial relationships that existed prior to cancer.

The age of individuals involves different challenges within the child-parent relationship. Experiencing cancer can change the dynamics of the parent/child relationship, which are influenced by the stage of development that AYAs are going through. For adolescents, independence from parents can be a relatively new concept. It can be difficult to accept that they could be even more dependent on their parents post-diagnosis, when this dependence is typically waning (Hilton et al., 2009). However, for young adults parental over-protectiveness is a common theme among AYA literature, alongside the stress of protecting parents to avoid worrying them (D'Agostino & Edelstein, 2013).

Friends and peers

The usefulness of support from friends and peers often varies. While friendships that existed prior to the cancer diagnosis can be very helpful for AYA, the developmental stage typical of adolescents can hinder their understanding and compassion for peers with cancer (Wakefield et al., 2013). AYAs have reported feeling more mature than their peers, which is suggestive of developmental incongruence, whereby AYAs are faced with significant issues such as death and physical impairments (Enskar & von Essen, 2007). Coping with such considerable issues can result in AYAs separating from their peers. It can also be particularly difficult for AYAs if and when they decide to tell their friends or peers about cancer, and the decision to share this information can be fraught with uncertainty over others' reaction to this news (Zebrack, 2011). Evan and Zeltzer (2006) and Zebrack (2011) suggest that the type of social support sought from others is likely to depend on the age of the young person and their peers – for example, the support sought by a young teen (13 years old) is likely to differ from that sought by an older teen (16 years or so), and this may affect who the AYA turns to for support based on what their needs are. AYAs are also at a heightened risk of social isolation when they are forced to miss chunks of school, particularly when they are having treatment or recovering from its' effects (Howard et al., 2014). However, social support from friends has been linked to positive affect in adolescents with cancer, which Wesley et al. (2013) suggest may encourage normalcy for these individuals alongside increased positive feelings. It appears that close and trustworthy friends can be very valuable for AYAs and the provision of social support.

Alliances with other survivors

Previous literature has well documented the value of social support from fellow cancer survivors for AYAs (Goldfarb & Casillas, 2014; Stegenga, 2014; Thompson et al., 2009). Research findings based on young adult survivors have purported that social support based interventions were beneficial for both increasing individual's social support and encouraging healthy behaviour changes (Rabin, Simpson, Morrow, & Pinto, 2013). Other studies have also highlighted the need for peer support, especially systems that provide opportunities for AYAs to meet other AYAs or those who have been through a similar experience (D'Agostino & Edelstein, 2013). The benefit of such support includes an insider understanding the trials and tribulations involved with cancer. In addition, AYAs' involvement in support groups has been shown to help individuals cope with stress and may also increase positive lifestyle changes (Brunet, Love, Ramphal, & Sabiston, 2014).

Online social support from other cancer survivors may be particularly useful for AYAs whose face-to-face support network does not meet the needs of the individual

(McLaughlin et al., 2012). A study by Love et al. (2012) examined the psychosocial support offered in an AYA online support group and found that informational and emotional support were the most prominent themes amongst discussions. This study found that members of the online group differentiated strongly between those within the group – fellow cancer survivors – and those in the 'out-group', or those who have not experienced cancer themselves.

This finding suggests the importance of the connection formed through the common experience of cancer and the cancer identity, particularly when other peers in this age group are likely to have little personal experience with cancer (Love et al., 2012). Research has also highlighted how online support groups enable AYAs to seek network support, compare stories and guidance on topics like moving on after treatment (Crook & Love, 2017). These forums also provide accessible support during times of treatment where young people cannot be around others (such as when they are immune compromised), and if AYAs live in remote geographical areas. However, Crook and Love (2017) also acknowledge the dark side to sharing stories online, where young people can discourage treatment adherence, or increase uncertainty regarding decision-making, at the cost of venting their experience to others.

Gender differences

It has been suggested that gender differences may occur with regards to some aspects of social support for AYAs. In terms of coping skills, there have been shown to be sex differences in ways that adolescents cope with cancer. Tremolada, Bonichini, Basso, and Pillon (2016) reported that girls are more likely to enlist their family and friends to aid in problem solving, whilst boys tend towards active coping strategies, for instance using physical or recreational activities. The authors hypothesised that women may criticise their perceived social support more than men because they are commonly more emotionally affected by stressful events (Tremolada et al., 2016). Furthermore, female AYAs have been seen to express their thoughts and feelings more than male AYAs (Kameny & Bearison, 2002), suggesting that particular consideration should be given to how males process their reaction to cancer. The interactions that male AYAs experience may be an insight to their reaction; for instance, if male AYAs report less emotional support than female AYAs, this may be due to males having fewer discussions pertaining to their thoughts and feelings. Nevertheless, contrasting gender differences exist in regards to the types of social support received. Research findings indicate that male AYA bone tumour survivors report higher general and tangible social support than female AYA bone tumour survivors (Teall et al., 2013). However it is not known if the female AYA survivors in this study received more or less informational and emotional support than their male counterparts. Thus, the perception of social support and coping skills for AYAs with cancer should be interpreted in light of reported gender differences.

Intimate relationships

Due to the nature of the adolescent and young adult development, it is important to consider the impact that cancer has on intimate relationships. It is likely that AYAs are at various stages of their experience of intimate and/or sexual relationships, and some AYAs will be married or may even have young children. Some AYAs found their relationships changed for the better through increased intimacy and the experience of going through cancer together; whereas for others, their relationships broke off or were severely strained due to the numerous challenges that cancer presented (Robinson, Miedema, & Easley, 2014). Unsurprisingly, research has demonstrated that experiencing cancer can have a detrimental effect on sexual intimacy for AYA, either due to the physical or mental effects of treatment, poorer body image or challenges to sexuality, such as – for women – feeling less feminine due to hair loss (Robinson et al., 2014). AYA survivors have also noted feelings of guilt associated with the financial strain put on their partners as a result of the illness (Pratt-Chapman, Willis, Bretsch, & Patierno, 2013). In addition, the issue of fertility being affected by cancer treatments is also pertinent, and may affect the intimate relationships that AYA are already part of, or how these are approached in the future.

AYAs commonly have relationships with a number of groups when they experience cancer: parents, friends and peers, intimate partners, and other survivors. Social support varies slightly between these groups as young people may require different support from each. Regardless of what social support looks like in each relationship, to maintain a healthy psychological state throughout this difficult time and to avoid social isolation and encourage normalcy, social support is an important element for young people affected by cancer.

Summary of literature

The research discussed thus far looks at the impact that cancer can have on young people and how it can affect their development. It has also addressed some of the psychosocial interactions that they encounter, and the reactions and responses of others toward these individuals and cancer. These interactions range from those considered helpful (as identified in previous studies), such as practical and emotional support, to those considered unhelpful or hurtful, such as avoidance and rude comments. The effect of these interactions on AYAs has been clearly described and linked to the perception of social support, levels of distress and impact on the likes of treatment adherence. Literature also outlines the connection between experiencing cancer as an AYA and how this affects the developmental challenges that all young people face. Dealing with issues such as mortality, infertility, drastic changes to physical appearance, the formation of their identities and missing large chunks of education or work has a significant impact on young people with cancer as it contradicts what is considered developmentally appropriate for their age.

Perhaps one of the most difficult developmental issues for AYAs though, is the change to their peer relationships, or their social network. Plenty of literature outlines the importance of peer relationships for young people, particularly adolescents, and this can shift the priority for AYAs from cancer to the effects on these relationships. As they place such high importance on peer relationships and peer acceptance, social rejection or feelings of being ostracised can be devastating. Their peers may have little experience of a young person with cancer and therefore be unsure what to say or do, which can translate to discomfort, avoidance or making hurtful comments. Combined, these factors result in a mismatch between AYAs' expectations and needs, and the support they receive. This disconnect has been well documented among the literature discussed in this review.

Gaps in existing research

The breadth of literature on this topic has increased significantly in the past fifteen years, and spans a number of continents across the world. Countries with more available research funding, for instance, the United States and the United Kingdom, produce a plethora of reputable studies. The literature mentioned in this review is largely based on AYAs from these countries, which is important to remember when interpreting findings. Little research has come from smaller countries with fewer AYAs, such as New Zealand. Given the aforementioned importance of psychosocial interactions for young people with cancer, it is remarkable that we know so little about AYAs' psychosocial experiences, and AYAs from Maori or Pacific Island backgrounds, in our own country.

In addition, while many studies related to the psychosocial effects of cancer on AYAs comment on the developmental age of this population, fewer studies examine the relationship between the experience of cancer and the impact on healthy development. Research that has discussed the connection between AYA cancer and development has largely focused on a specific area of developmental impact, such as identity (Cantrell & Conte, 2009; Drew, 2007; Jones et al., 2011; Lewis et al., 2013). Gibbs (2002) discussed the effects of cancer on development in relation to Erikson's stages of psychosocial development. Gibbs' research however, does not consider psychosocial interactions in relation to development. There are also few studies that have included a longitudinal approach over a one year timeframe to attempt to distinguish how both adolescents and young adult's development continues to be affected by cancer.

The qualitative interviews by Zebrack et al. (2010) appear to be the closest example of categorizing AYAs psychosocial interactions, where the authors organised participants' raw data into one of four types of social support. Identifying types of interactions is sufficient for examining the frequency of these interactions; however, as yet, there is a lack of thorough examination of which interactions may take place. A model that organises interactions into categories is best approached with a comprehensive range of interactions, and currently there appears to be no consumer-organised models of interactions. Without models organised by AYAs themselves it is difficult to understand how this population perceive social interactions. To further understand the developmental effects of cancer, this study aims to create a model of adolescent, and a model of young adult interactions, that is derived from existing literature, previous work by the author, and data obtained by interviewing AYAs in NZ. It is essential to understand these effects in order to make recommendations for clinicians working with this population, or to create resources targeted at AYAs themselves and their support network.

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Chapter Three

Methodological positioning

Epistemology/Ontology

My philosophical perspective that informed the epistemological basis of the research aligns best with the social constructionism paradigm. This is embedded in my value of the subjective experiences of young people and the belief that people construct their own representations of reality. Social constructionism opposes positivist beliefs that knowledge is based on objective facts, and instead emphasises that people construct their own subjective knowledge (Raskin, 2002). Given that this paradigm postulates that knowledge is constructed through a person's social interactions (Burr, 2006), it appeared to be particularly suitable for this study. This theoretical foundation also encompasses the role of the researcher in the research process (Jankowski, Clark, & Ivey, 2000), and as I felt it was beneficial to disclose my cancer experience to participants, this seemed a natural fit. This epistemological and ontological foundation naturally informed the methodological approach to this research.

Qualitative research employs a holistic approach towards describing people's behaviour in a naturalistic sense, and attempts to understand participants' worldviews through their own eyes (Taylor, Bogdan, & DeVault, 2015). It is appropriate when researchers are interested in acquiring a thorough understanding of how people think about a topic, and to intricately explore the perspectives of participants. As one of the core aims of the research involved exploring AYAs' experiences of psychosocial interactions, a qualitative approach was appropriate to best understand participants' perceptions of their experiences. Constructionist theory determines that a part of qualitative research encompasses the role of the researcher in the research process, and the relationship between the researcher and participants (Jankowski et al., 2000). Interviewing participants was the most appropriate way to learn these experiences and make sense of these in a meaningful way. Furthermore, I felt it was important to not only disclose my experience of cancer to participants, but also to discuss my personal reflections throughout the research in the thesis. I chose to interweave these throughout chapters to reflect the notion that my personal experience of cancer affected each stage and evolved with the research.

Theoretically, the underpinnings of qualitative research that determine the significance of participants' subjective experience for knowledge and the acknowledgement of multiple realities, were also upheld in the epistemological basis for the card-sort study. The quantitative study was interested in the conceptual dimensions that inform the perception of psychosocial interactions, which acknowledges the subjective basis for each individual's experience of cancer. This is reflected in the open GOPA card-sort design, which was employed because this was an exploratory study and because this method allowed participants to categorise the items in the way that they perceived them to be similar or opposing. Our grouping of items for the overall model, which averaged the individual results of course, lessened the individually subjective lens by which we can understand the conceptualisation of dimensions. However, an element of the analysis for the model involved qualitative analysis, which was through my interpretation of the results. Overall, the theoretical basis for both qualitative and quantitative studies is related, and both reflect the research questions and aims.

Rationale for mixed methods

Cancer is a sensitive topic, and it often broaches intense feelings in people. Having previously conducted a quantitative study on psychosocial interactions for my

Honours project (Cameron, 2015), it felt appropriate and necessary to talk face-to-face with young people when I decided to ask them about their experiences with cancer. We identified that we needed psychosocial interactions that were specific to AYAs for a new model. The first conversations my supervisors and I had were around how to expand on the multidimensional model formed in the Honours study, and apply this to the AYA age group. The Honours adult model used items formed from a literature search, and there is plenty of research on social interactions and social support of adults with cancer. However, it seemed inappropriate to use items taken from international research for this study. The only way we could ensure that items for the model were applicable to the New Zealand culture and AYA population was to conduct interviews with AYAs in New Zealand and gather items from there. Previous studies have also utilised interviews or focus groups as a means for acquiring appropriate items for MDS mapping (Harvey, Bimler, Evans, Kirkland, & Pechtel, 2012; Hydeman, Uwazurike, Adeyemi, & Beaupin, 2019; Marwick, 2016; Mujumdar, Lanzarini, Lowe, Bolinder, & Doleh, 2018). Harloff and Coxon (2007) recommend one method for attaining items for sorting is through focus groups, and by interviewing participants we followed a similar method.

Relating the findings of the AYA model to the qualitative results was fitting because the interactions sorted in the model were partially derived from the interviews. In addition, as we had seen consistency with the literature for most themes in the interviews, it was important to consider how the model findings related to the interviews too, in addition to the literature itself.

Dual aims of qualitative and quantitative studies

During the analysis of the first interviews it became apparent that all participants referred to, or were affected by, aspects of developmental change. The developmental impact was so clear that it was too obvious to ignore, and therefore, we questioned what the impact would look like one year following. As we had time to complete interviews a year later, it was decided that we could interview at two time points to establish whether the impact changed over the one year time period. Furthermore, I felt I needed to maximise the analysis of the data to do justice to the participants' time and stories. As well as respecting the information participants were sharing with me, I believed I could add to the literature on AYAs' psychosocial experiences. In the current literature on the topic, most – if not all – research acknowledges and/or examines the impact that cancer can have on young people's development. Looking back on this, it would have been difficult to discuss the results of the analysis and ignore development, as research points to this being a crucial aspect to AYAs experiences. Therefore, we decided to make two main aims for the interviews: both items to inform the quantitative study through an exploration of psychosocial experiences, and the developmental impact on young people as a result of experiencing cancer.

Qualitative methodology

Thematic analysis

Thematic analysis is a helpful way to explore the insight into AYAs' experiences of interactions and the impact on their development through identifying themes and patterns of meaning across participants' stories (Braun & Clarke, 2006). While I was asking participants specific questions about young people's experiences and the developmental impact, thematic analysis allowed me to identify commonalities among their experiences. Qualitative research does not emphasise numbers in its analysis but it is useful to prioritise themes that all participants related to or that were more common. Vaismoradi, Jones, Turunen, and Snelgrove (2016) state that "while the importance of a theme can be influenced by its level of frequency throughout data, it should rather capture something important in relation to the overall research question" (p. 105).

When considering the frequency of themes occurring in the data, more common themes are more trustworthy as there is more evidence for them; however, we aimed for trustworthiness instead of generalisability. Less common themes are important too, as they highlight the unique situation for some young people, such as the two participants who experienced a parent passing away early into their survivorship period. These losses had an understandably profound effect on the young people and it was important to include this theme to honour their stories and to demonstrate the variability in the data.

Social support/social interactions

When determining whether to ask specifically about social support I considered how social support is defined in the literature. What became apparent is that what determines if interactions or responses are deemed supportive or not is how AYAs perceive these. Ultimately I needed to allow space for young people to decide this without prefacing my question with the context of 'social support' in the event that the question was interpreted as only including supportive interactions. This gave young people the opportunity to share their subjective experiences. This decision was also embedded in an understanding that the definition of social support differs slightly, and the perception of interactions or responses is shaped by individual experiences and development. Avoiding the term social support encouraged participants to speak to all social experiences, rather than limiting their answers to positive social experiences.

Furthermore, I considered it respectful to allow space for young people to tell me about their experiences, whether they were supportive or not. Also I was conscious of the researcher-participant power imbalance and I wanted to ensure that I framed questions in a developmentally appropriate way to avoid misunderstanding or misinterpretation. I felt that using the words "helpful" and "unhelpful" were clearer for this age group and had less chance of being misunderstood.

Sample size and data saturation

Evidence suggests 6-10 participants is likely to achieve saturation (Braun & Clarke, 2006; Stegenga & Macpherson, 2014). We left the prospect of interviewing more participants' open in case we did not achieve data saturation with 10 participants. We concluded that as we were not gathering any new information towards the last few interviews, saturation had occurred.

Further evidence that saturation was achieved is that if saturation had not been achieved with the sample in the first interviews, this would have been evident in the quantitative study, as one function of the model was to confirm the interactions gathered in the interviews were sufficiently comprehensive. We understood that if saturation was not achieved and there were substantial interactions missing, there would also be substantial gaps in the model. Although there were gaps identified these were not substantial and could be attributed to gaps in literature also. Conversely, the items included from the adult model may have filled in gaps in the AYA model, meaning we are unable to decisively confirm whether saturation was achieved, and what the gaps in the AYA model resulted from.

Follow-up interviews

After analysis of the first interviews and upon noting that their experiences of social interactions seemed to be associated with their developmental stage, it became apparent that participants would be moving between high school and university, or university and work, over the year following these interviews. We decided we could gather important data on the shift in their perspective of interactions if we completed additional interviews one year on. We realised that it would be unrealistic to capture shifts in developmental stages in one year; however, we aimed to capture the impact cancer had on their developmental trajectory. As we initially did not plan to have the follow-up interviews, we did not accommodate for appropriate attrition. Had we planned to do these interviews we would have aimed for a larger initial sample size; however, we chose to maximise the data intake from the sample we had. This is consistent with the concept of action research, where the researcher is involved in a reflective process including taking steps to improve the social situation of the research - a methodology integrating research, action and analysis (Somekh, 1995).

Multiple studies have used a longitudinal design to identify the impact cancer has on AYAs' development. Stegenga and Macpherson (2014) utilised a longitudinal design to interview AYAs on the impact of cancer on their identity formation. Straehla et al. (2017) assessed the benefit and burden finding of AYAs, including changed sense of self, relationships, philosophy of life and physical well-being. They conducted interviews with AYAs within two months of diagnosis, then 6-12 and 12-18 months later. Results showed perceptions of benefits and burdens evolved over time, focusing less on physical difficulties and more on personal strengths and life purpose (Straehla et al., 2017). This study particularly demonstrates the ability to highlight developmental change over a one-year timeframe. Lehmann et al. (2014) conducted a study in Sweden over 10 years, examining the negative and positive consequences of adolescent cancer. They interviewed participants at 3, 4 and 10 years following diagnosis and included aspects of development such as fertility concerns, existential thoughts about loss and life, sense of self and close relationships. Therefore previous studies utilising a longitudinal design demonstrated the effectiveness of this approach in understanding the developmental effects of cancer in young people.

Quantitative methodology

Rationale

At the outset of the research process we identified the lack of multidimensional models of psychosocial interactions for AYAs, and people with cancer in general. One of the research questions specific to the quantitative study addressed how relevant the model I developed in my Honours research was for AYAs. Given the exploratory nature of the AYA model, we deemed it relevant to build on and adapt the Honours model.

The purpose of the quantitative study was to understand the relationships between psychosocial interactions relevant to AYAs with cancer. Hierarchical Cluster Analysis (HCA) and Multidimensional Scaling (MDS) were used to form a three-dimensional model of these interactions, which provides the proximal distance between interactions based on the organisation of the cards in a GOPA (Group, Opposite, Partition, Add) format. Through the use of MDS, clusters of interactions and dimensions were identified within the model, highlighting perceptual differences and similarities among the data. The model helps to provide an understanding of the relationships between interactions in a similar way to how a globe represents the approximate distances between countries. AYA survivors were asked to complete this card-sorting task as they have knowledge of these interactions and many are likely to have experienced a large portion of the interactions with other people.

Methodology

When considering the methodology I would like to provide a very brief rationale for choosing a GOPA card-sort, HCA and MDS analyses. Much more detailed descriptions of each of these processes are outlined in Chapter Five, prior to the article for the quantitative study.

Group, Opposite, Partition, Add (GOPA) procedure

Harloff and Coxon (2007) advise that sorting data is an appropriate way to evaluate how people organise items on a perceptual or conceptual level. They discuss that open sorting is appropriate when categories for items are not known, which is suitable in the case of our exploratory study. Furthermore, the function that sorting items serves – to establish how participants conceptualise data – directly related to our research aims of understanding how AYAs' group interactions and which they perceive as opposing.

The GOPA sorting method is a type of hierarchical sorting, of which there are a number of approaches. Opposite sorting, introduced by Bimler and Kirkland, allowed for major axis of variance to be identified, and for dissimilarity data to be available for MDS, improving the reliability of the solution (Harloff & Coxon, 2007). Harloff and Coxon (2007) write that the greatest dissimilarities are not reliably determined if sorting results rely on similarity data from co-occurrences alone. The cumulative effect of all four steps of the GOPA card-sorting task results in conceptual clarity of the differences between items and clusters of items, as perceived by participants.

Hierarchical Cluster Analysis (HCA)

HCA has been commonly applied to sorting data, and is appropriate for data reflecting hierarchical relationships provided by hierarchy construction (Harloff & Coxon, 2007). HCA and MDS are complementary analyses that give alternate understandings on the similarity matrix. They emphasise different features of the data which is why it is important to use these together.

HCA organises items into clusters using the co-occurrence values: the step-wise grouping of items includes both initial clusters and the merging of similar clusters into larger groups (Marwick, 2016). The dendrogram created in HCA is used as a dissimilarity measure by taking the length of the shortest path connecting items and dividing this by two, which forms a dissimilarity matrix to be analysed by MDS (Marwick, 2016). The dendrogram created by HCA can later be used to validate the items presented in the MDS model, as a means of qualitative analysis.

Multidimensional Scaling (MDS)

According to Harloff and Coxon (2007), MDS was one of the first analysis methods applied to sorting data. MDS was the chosen approach for this study because it provides an implicit model of the way young people perceive psychosocial interactions. MDS produces a model of underlying conceptual relationships in the data by using spatial representation, which cannot be achieved using Factor Analysis. Through MDS's organisation of items into clusters, a framework is developed for understanding AYAs' perceptions of psychosocial interactions, which contributes to the aims of the quantitative study.

When using dendrograms there is always a dominance of a group of large distance values between items, and using a set of variants of sorting avoids condensed groups and circles which could be a consequence of methodological processes (Harloff & Coxon, 2007). Nonmetric MDS has the capability of managing some omitted items - which did occur in our study - as MDS simply utilises the items that have been included. Obviously this affects the reliability of the overall model if there is a significant portion of data missing. Fortunately, in this study there were minimal data omitted.

Conclusion

This chapter has outlined the epistemological underpinnings of this research, which informs the methodological approach taken overall. The rationale for choosing to use mixed methods was also discussed, as well as an explanation of the qualitative and quantitative methodologies. Further discussion of the quantitative methodology is included in Chapter Five. There are brief descriptions of these methods repeated in the respective journal articles.

Chapter Four

Introduction to qualitative interviews

The following article is based on the qualitative part of this thesis. That is, interviews with AYAs in 2015 and follow-up interviews with the same sample in 2016. This study has been reviewed and approved by the Central Health and Disability Ethics Committee New Zealand on the 3rd August 2015 based on the full review pathway – application 15/CEN/76.

The following article has been accepted for publication by the Cancer Nursing journal, dated March 2019.

The psychosocial interactions of Adolescent and Young Adult (AYA) cancer survivors and the possible relationship with their development

Background:

Adolescents and Young Adults (AYA)

According to the Adolescent and Young Adult (AYA) Cancer Incidence and Survival in New Zealand report, between 2000 and 2009 there were on average 160 new cases of cancer in adolescents and young adults[1] (aged 15-24) each year in New Zealand (Ballantine & Sullivan, 2013). The most recent statistics in New Zealand for AYA cancer refer to 2015, where there were 168 new diagnoses in the 16-24 age range (Bradbeer & Ballantine, 2015; Ministry of Health, 2017). Furthermore, cancer is the leading cause of non-accidental death in AYAs in developed countries (Padhye & Gabriel, 2013), indicating the impact of the illness for this age group. Social support is important because it has been shown to impact on AYAs' treatment adherence and this in turn may influence short- and long-term health outcomes (McGrady, Brown, & Pai, 2016). An increasing number of studies have shown that the psychosocial issues facing cancer survivors who were diagnosed as AYAs are unique to this age group, separating them from those issues present in cancer survivors who were children or adults when diagnosed (D'Agostino & Edelstein, 2013; Richter et al., 2015). Literature demonstrates that AYAs experience numerous psychosocial effects including the impact on their identities and development, and this is currently a focus for research internationally (Dobinson et al., 2016; Lang, Giese-Davis, Patton, & Campbell, 2018; Patterson, McDonald, Zebrack, & Medlow,

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[1] The term AYA is interpreted more or less liberally among different countries, with some research separating adolescents (anywhere between 12-19) and young adults (anywhere between 20-39). While the definition of AYA is 12-24 in New Zealand, for the purposes of this research, AYA refers to 16-25 year olds as this is within the more commonly accepted age range internationally. The upper age limit of 25 includes young people who have recently outgrown CanTeen New Zealand (as their upper age range is 24), and therefore this maximizes participant inclusion. The New Zealand AYA Standards of Care document outlines that "the upper age limit should be indicative, rather than absolute, dependent on the disease type and developmental needs of the individual; sometimes, this guidance will be appropriate for those aged up to 30 years"(Pettit & Watson, 2016)(p.5).

2015). Additionally, research has shown a link between distress and unmet health, physical and psychological needs for AYAs (Dyson et al., 2012; Halvorsen et al., 2018; Quinn et al., 2015), as well as demonstrating developmental effects of cancer, such as the effect on AYAs' education, sexuality, family planning, and their identity formation (Barnett et al., 2016; Richter et al., 2015). AYA survivors are also at higher risk of psychosocial distress and developing mood disorders than their peers (Lang et al., 2018). Thus, the psychosocial wellbeing (including mental health, and outlook on life) of AYAs and their social interactions can make a considerable impact – positive or negative - on their experience with cancer survivorship.

For the purposes of this study, psychosocial interactions are defined as verbal and non-verbal (ignoring, body actions such as nodding, staring) transactions between the AYA and someone else. These interactions can be social and therefore purposeful, or they may be non-purposeful and have psychological implications for the AYA (such as the effects of feeling ignored or being stared at). Lally et al. (2013) defined unsupportive social interactions as those upsetting and between two people who have some form of social relationship, therefore excluding interactions with strangers. However, Lally et al. (2013) included both intentional and non-intentional interactions in their definition as interactions were based on how they affected the person with cancer, rather than whether they were purposefully upsetting. Shapiro (1990) noted psychosocial interactions (in the form of doctor and patient interactions) include communication which is sensitive to the recipient's feelings and thus likely purposeful. Both of these studies together define psychosocial interactions consistent with our definition.

Development

Use of the human development theory (Erikson, 1970a; Kivnick & Wells, 2014) lends itself to the exploration of developmental and psychosocial effects of having survived cancer diagnosed as an AYA. Erikson believed that the adolescence psychosocial stage (ages 13-19) encompassed the theme of fidelity, where individuals are conflicted between identity vs. confusion, whereas the young adulthood stage (ages 20-39) emphasised love, with a conflict between intimacy vs. isolation (Kivnick & Wells, 2014). Erikson viewed the adolescence and young adult periods as highly significant in a person's life as this is when the individual experiences identity confusion, eventually reaching a crisis (Erikson, 1970a). He saw adolescence as a critical period, entailing the gradual learning of morality and ethical thinking (Erikson, 1970b). Thus, the AYA stage is perceived as a time of substantial individual growth and change. This is also timely when young people are diagnosed with cancer; as such a significant diagnosis can spur ethical and moral discussion and decision-making.

Identity formation can be a key developmental process for young people (ages 13-19 according to Erikson) and this process has been identified as more challenging for AYAs due to the possible conflict between the cancer and survivor identities (Jones et al., 2011). In 2002, Gibbs (2002) studied the psychosocial effects of cancer on 11 young adult survivors of Hodgkin Lymphoma diagnosed in their 20s and 30s, looking specifically at the effect on development in relation to Erikson's theory of development. In terms of identity, participants appeared to be incorporating survivorship into their identity, although some struggled with their autonomy, particularly those who felt they had partially lost this during the treatment process. Some survivors fought to find an appropriate place for cancer within their identities, and several survivors felt their identities had been altered so extensively that they felt distinctly different from their peers. In particular, facing thoughts about death and mortality clashed significantly with the 'normal' developmental stages of peers (Enskar & von Essen, 2007). Overall findings showed that survivors appeared embroiled in earlier developmental conflicts and were actually less concerned with identity than the comparison group (Gibbs, 2002). Gibbs (2002) concluded that this discrepancy could occur because cancer can threaten an individual's fundamental understanding of the world, resulting in regression to earlier developmental challenges that they may have already surpassed.

Similarly, Williams et al. (2013) identified regressional developmental stages in adolescent cancer survivors; however, they found that family structure and routine was likely to support adolescents to maintain their identities by enhancing control and predictability in their everyday lives. Soanes and Gibson (2018) also reported young adult survivors noting their transition to a 'patient' identity, and the desire to exercise control over their lives and hold on to their former identity. Cantrell and Conte (2009) studied young adult survivors of childhood cancer (those diagnosed as adolescents), finding these individuals experienced the burden of others' unrealistic expectations for how to live their lives. Specifically, survivors reported feeling unable to "experience the usual negative lows young adults experience because they are different in having survived cancer" (p. 320) (Cantrell & Conte, 2009). Stegenga and Macpherson (2014) reported the longitudinal effects of cancer on the identity formation of adolescent patients at four stages from two-months post diagnosis. Their findings highlighted three types of identities evident throughout the year following diagnosis: the adolescent identity, the cancer identity, and an integrated adolescent with cancer identity. They found that participants continually struggled to negotiate how their adolescent and cancer identities fit together, particularly as they struggled with peers and adults adjusting to their physical and emotional changes after diagnosis and throughout treatment (Stegenga & Macpherson, 2014).

Social Support

The developmental importance of social support for AYAs is evident in the literature. Research has identified that emotional and practical support from a partner, family or another trusted person is directly related to AYAs' quality of life and perspective on their cancer experience (Kent, Parry, Sender, Morris, & Anton-Culver, 2012). As adolescents often live with at least one other family member, family are often considered the main source of support, both practically and emotionally (Wakefield et al., 2013). While age-respective peers can be very helpful for AYAs, the developmental stage typical of adolescents can hinder their understanding of cancer (Wakefield et al., 2013) and could limit their empathy towards AYAs. Research has shown social isolation to be an evolving, rather than a static, issue for adult survivors of childhood cancer throughout survivorship

(Howard et al., 2014). Zebrack, Chesler and Kaplan (2010) looked at behaviors that were helpful and hurtful for AYAs to establish their effect on their overall well-being. Of the social support behaviors, positive attention (in the form of gifts or visits from others) and the promotion of normality were considered helpful, alongside the emotional and practical support from other AYA survivors because of their shared experience. Hurtful behaviors included negative or lack of attention, and denying or dismissing experience. Healthy peers may be distressed by a cancer diagnosis and therefore avoid AYAs (Zebrack & Isaacson, 2012). Negative attention was further included as inappropriate comments, laughter or teasing, over-protective parents or feeling uncomfortable due to the approach of mental health professionals. Overall, participants confirmed the importance of interpersonal support, suggesting that social support - and negative behaviors - can considerably impact their experience with cancer (Zebrack et al., 2010). These findings support those of Williamson et al. (2010), who found adolescents with cancer had difficulty managing negative reactions to changes in their physical appearance, in addition to the distressing experience of coping with 'shocked' reactions by others. The authors also found the adolescents' friends who provided positive feedback on their appearance changes were instrumental in assisting the patients to accept these changes (Williamson et al., 2010).

Social support from peers has been linked to positive affect in adolescent AYAs, and Wesley et al. (2013) suggest social support may encourage normal socialisation alongside increased positive feelings. A systematic review of literature showed AYAs have reported the importance of connecting with other AYAs and their desire for more support from this population (Tsangaris et al., 2014). One study identified that opportunities to meet other AYAs who had experienced cancer were rated as more important than support from family and friends, and connecting with other AYAs and peers in general also encourages a sense of group identity, a core developmental task common to young people (Zebrack, Bleyer, Albritton, Medearis, & Tang, 2006). Connecting AYAs with appropriate AYA survivors can serve as social support and role models to instill hope in patients for those who have recently completed treatment (Zebrack & Isaacson, 2012).

The present study

Currently, in New Zealand there is no research on the psychosocial effects of AYA cancer, or the impact cancer has on young people's development. This study is the first research that the authors are aware of that addresses this issue in the New Zealand population, particularly with a high ratio of Maori and Pacific Island participants to New Zealand European participants (participants identifying as Maori or Pacific Island constituted sixty percent of the participant sample). Furthermore, there is little current research examining AYAs' psychosocial interactions and how their development is impacted by these across a one-year time lapse, which this study addresses. Given the importance of social support for the AYA population it is imperative to more fully understand their psychosocial interactions. This study aims to identify what social support is helpful and unhelpful for AYAs, with particular focus on the gaps that might exist in order for future studies to address how clinicians, support agencies, and families and friends can improve these. One year follow-up interviews were conducted to identify whether time and age affects AYAs' perception of their psychosocial interactions, and whether a one-year time lapse affects the developmental impact on these young people.

This research also examines the developmental impact of cancer on AYAs after a one-year time lapse, an aspect that is largely unique to this study. The closest research we could identify to this study is that of Stegenga and Macpherson (2014), who focused on the developmental impact on adolescents post-diagnosis, and particularly their challenges with identity formation. The current study differs to that research because we focus on the adolescent *and* young adult population, our participants were all at least six months post-treatment, and we consider psychosocial interactions in light of the broad developmental impact. Looking to gain a better understanding of how experiencing cancer interacts with the developmental stage of AYAs is an important pathway to offering the appropriate type of support to this population. This is particularly relevant for clinicians who support AYAs in the aftermath of cancer treatment, and assist these young people to identify their 'new normal' and how cancer integrates into their existing identities.

Method:

Recruitment

Ethical consent was sought and approved by the Central Health and Disability Ethics Committee New Zealand. Participants were approached through a specific support group in New Zealand with the objective of recruiting ten members to participate in the study. Data saturation was expected to occur at this sample size, however flexibility existed for increasing the sample. Contact was made by the lead author to national and provincial support group offices. Support group workers asked members if they wished to participate, and those who did contacted the lead author. Brief phone calls were then arranged with members to discuss inclusion criteria and once it was established that criteria were satisfied, to organise an interview. Inclusion criteria stated all participants must be between 16-25 years, that treatment must have concluded at least six months previously and preferably within three years of participation. Nine participants were recruited through the support group. A national press release was also circulated and one participant made contact after seeing a local newspaper article that resulted from this. Participants either received information sheets through the support group or these were emailed prior to the interview, and consent forms were signed at the time of interview (one participant posted the form).

Procedure

Nine interviews took place in person, and one was conducted by telephone (at the participant's request). Interview questions were based on two main categories: psychosocial interactions, and developmental impacts of cancer. Interview questions were semi-structured, with questions regarding psychosocial interactions asking about: helpful and unhelpful responses to cancer from others, and advice for newly diagnosed AYAs. The main study question for this part of the interview was, "Can you tell me about how people have responded to you having cancer?" Probes related to specific interactions that were helpful and unhelpful, frequently asked questions, advice for newly diagnosed AYAs and whether there is anything they would change about people's responses to cancer in young people. The developmental questions related to: identity, age of diagnosis, the meaning of cancer, and other developmental interruptions. The main study questions for the developmental part of the interview were, "What does it mean to you to have cancer as a young person?", "What differences do you think there are between having cancer as a young person and having cancer as an adult?", "How do you think cancer has affected your life?", "Has experiencing cancer prevented you from doing anything your friends are doing?", and lastly, "Has cancer affected your sense of who you are, or how you view yourself?". Interview questions were written by the first three authors, however all interviews were conducted by the first author. The first author has personal experience as an AYA cancer survivor and is in a clinical psychology training program, and the second and third authors have professional experience as clinical psychologists working with cancer patients and survivors (both AYA and adult). Most interviews took between 45-90 minutes. Data saturation was evident by the tenth interview. The benefits and risks of participation were discussed with AYAs at the outset prior to interviews began, and were outlined in the information sheets that participants were given. All participants were screened for emotional distress at the conclusion of the interview, and offered a referral to a mental health professional if they reported distress. Participants were able to access support services through the support group or were advised to contact their health professional if they became distressed following the interview. All data was held in a confidential manner and stored securely.

Participants

For developmental purposes the sample was split into an adolescent group of four participants (aged between 16-19 at the time of this study) and a young adult group of six participants (aged between 20-25). These ages were selected based on those

AYAs who were adolescents when treated and mainly at high school, and those who mostly young adults when treated, and perhaps at university or in the workforce. The mean age of the younger participants was 17.5 years, and the mean age of the older participants was 23.2 years. Participants' overall mean age was 20.9 years, with an equal gender split. Of the ten participants, three described themselves as New Zealand European or Pakeha, one as New Zealand Maori, one as Tokelauan, two as both New Zealand European and New Zealand Maori, two as both New Zealand European and Cook Island Maori, and one did not disclose their ethnicity. Participants had been diagnosed with a heterogeneous group of cancers with three having been diagnosed with Leukemia, two with Lymphomas, two with a brain tumour and one participant each with Thyroid Cancer, Osteosarcoma and Sarcoma. Participants had undergone a range of treatments with eight having had surgery, seven chemotherapy, seven radiation therapy and three a stem cell transplant. The names of participants have been changed.

Follow-up interviews

These interviews were conducted approximately twelve months after the first interviews, and all eligible participants from the first interviews were emailed an invitation to participate. The first author also completed all follow up interviews. There was a fifty-percent participant response rate for the follow-up interviews. One young person declined the invitation saying she was too busy with university commitments to participate, and the other four non-participants did not specify a reason. Five participants agreed to participate, including three female and two male, with a mean age of 21.8 years. One participant provided a written response to interview questions, two participants were interviewed in person, one over the phone and one via Skype. Interview questions mirrored those in the first interviews to measure differences in developmental impact and psychosocial interactions, and questions regarding changes in the last twelve months, and new disclosures were also included.

Analysis

All interviews were recorded (except the written account) with participant consent and transcripts were analysed by thematic analysis (Braun & Clarke, 2006). According to Braun and Clarke (2006), thematic analysis “is a method for identifying, analysing and reporting patterns (themes) within data” (p. 79). A number of general patterns were identified from the transcripts, evidenced in the sections below and categorised by the identified themes. The first author completed most of the analysis, with assistance from the second and third author. Yardley (2000) described four characteristics of good qualitative research to determine rigour: sensitivity to context; commitment and rigour; transparency and coherence; and impact and importance. We addressed sensitivity to context by the first author’s self-disclosure of her own cancer experience as an adolescent. The purpose of this was to reduce the power imbalance between the interviewer and participants, and to create a safe environment where participants felt validated. Commitment and rigour was enhanced by the authors’ personal and professional experiences of young people and cancer, by discussion with co-authors throughout the analysis, and by validating the data from the first interviews at the follow-ups. Transparency and coherence was addressed by clear transcription and the use of quotes to support our interpretations of the data. Finally, impact and importance was established by comparing our results with the findings of other studies.

Results:

Initial interviews (2015)

Thematic analysis resulted in six identified themes among the data. These themes were labelled ‘Personal privacy and sharing of information’, ‘Independence’, ‘Identity formation’, ‘Positivity’, ‘Acknowledgement vs. being treated normally’, and ‘Support instead of supporting others’. All six themes applied to both Adolescents (A; aged 16-19) and Young Adults (YA; aged 20-25), and the relevance of each theme to the two age groups is described below.

Personal privacy and sharing of information

Participants spoke about the difficulty of maintaining personal privacy boundaries with parents and other family, or those visiting in hospital. A number of participants addressed their discomfort with sharing private details about their bodies with acquaintances or people they did not know well – or when family members shared personal details without seeking permission to do so - and discussed how awkward it can become to avoid answering personal questions - "You can become a bit more of an object than a person there for a bit" (Robert, YA). However, while privacy was important to participants, they were largely aware that at times this came at the expense of others' speculation. Consequently, participants welcomed carefully-timed and respectful questions and preferred to be asked than for people to whisper, gossip or make false assumptions. There was a recognition among most participants that others were naturally inquisitive about cancer and their experience, and for some people they would not have known a young person to have had cancer before - "I'm okay with questions and okay with being open about it, I was sort of just asked straight away so that was good" (Matthew, YA). Therefore, participants shared information - when appropriately requested – to dispel myths and encourage a positive but realistic public understanding of cancer, and also to maintain their ownership of their personal information. Literature has previously reported that young people choose to share cancer-related information with peers to debunk myths, avoid further questions and end rumours (Williamson et al., 2010).

Independence

Young adult participants spoke of experiencing newfound independence from their parents prior to cancer, only to discover that alongside the cancer diagnosis comes increased dependence on their parents - "I had to drop out… quit my job and move back home with mum… I was pretty new to experiencing adulthood, being independent and living out on my own and making my own decisions and then I just got stopped and thrown right back into home." (Matthew, YA). These participants found it difficult to again rely on their parents (or others in general), symbolic of a regression in their development. Such regression creates incongruency in developmental stages and distinguishes AYAs from their increasingly autonomous peers. Furthermore, a sense of loss occurred for some participants when acknowledging that they required physical, emotional and financial support, despite having recently acquired (or started the process of gaining) autonomy. Erikson proposed that adolescence and young adulthood involved a gradual separation from parents towards independence and autonomy (Kivnick & Wells, 2014). Younger participants also acknowledged their reduced independence, but most still lived at home and were fundamentally reliant on their parents before their diagnosis. One adolescent viewed this as a positive, saying "you're still… really sheltered… you're not expected to… shoulder everything like an adult" (Sarah, A).

Identity formation

While most participants made some reference to the impact of cancer on their identity, this appeared more profound in younger (16-19 year old) participants. Adolescent participants appeared more likely to express feeling that their personal identity and cancer had become merged due to others who "just all of a sudden think that me and cancer were the same thing" (Lisa, A). One high-school aged participant feared she would be known as "the girl with cancer" at her school for some time. It may be likely that adolescents are more susceptible to cancer impacting their identity formation due to their developmental stage, as well as the strong desire to fit in with peers – a desire characteristic of the adolescence period. The 'sick patient' role threatens the young person's ability to be perceived as 'normal', and consequently was rejected by participants. One young adult participant reflected back on his experience and said, "You don't get to find out who you are, and then suddenly you've got this label and you've been told who you are… You're so much more than f***ing hospital beds and… short hair or no hair, you know?" (Jon, YA). The young person can find themselves facing changing self-perceptions of their identity, and the 'cancer' identity does not necessarily integrate easily with the identity the AYA was forming prior to cancer - "…they might still think of me as the person with cancer but I'd like to think that I've kind of broken away from that now, and I'm now just me… Lisa 2.0.You know? Lisa post-cancer" (Lisa, A).

Older participants (20-25 year olds) also referred to the disruption of developmental trajectories, with one participant depicting the impact of cancer on identity as “your innocence, kind of stolen”, because “you miss out on growing up” (Jon, YA). The effect of feeling as though AYAs have missed out “on growing up” may result in a sense of being rushed into adulthood, potentially preventing AYAs from experiencing crucial stages in their identity formation. This was experienced by a young adult who stated, “Well it kind of made me grow up a bit… I was quite a childish person, had a really bad attitude with life. So uh, it… kind of taught me that you know life can be taken from you that easily” (James, YA). However the young adults’ identities were inclined to be more established than younger participants (16-19 years) because they had already navigated adolescence prior to diagnosis. In general, many participants acknowledged that cancer had contributed to who they were as people today, and this was not always viewed negatively - “I’ve proven to myself that I’m a fighter I guess. And when the going gets tough, then… I’m okay with it” Matthew (YA). The conflict between attributing cancer to something that had made them stronger, but not something that dominated their identity, was a difficult paradox to negotiate - “I don’t like how it defines you… but it makes you who you are as well” (Sarah, A).

Positivity

Experiencing cancer was reported to have a number of positive effects for participants. Revised priorities was a common theme among participants, with most identifying new purpose in life and the importance of surrounding themselves with supportive, positive people. Remaining positive about the cancer experience was commonly addressed (“every day is a good day” (Hannah, YA)), and the majority of participants were adamant that it was imperative to “make the most of this s****y situation” (Jon, YA) in order to mentally stay strong. The importance of remaining positive was exemplified by the statement that “the way that they see their situation is half of the fight … as bad as cancer is in itself, I find that it often brings out the best in people” (Matthew, YA). Matthew particularly emphasised the importance of retaining a positive outlook despite being substantially physically affected by cancer, stating "The way I saw it… I don't have a leg. I can't change that but, the one thing that I can sort of change is the way that I see it." Nearly all participants commented that they were enriched by their experience and stronger for it; however those who reported having more insight and viewed the experience more positively were also those who reported less negative social interactions.

Nonetheless, embracing a positive outlook partially contradicts participants' discussion of the substantial difficulties and challenges that cancer poses. This conflict is evident in the first quote by Matthew, where he resolves that perspective takes precedence over both the positives and negatives of the experience.
In many instances participants also commented that, despite experiencing developmental interruptions, they preferred to experience cancer as a young person rather than be faced with cancer later on in their lives. Participants described this as, "probably the best time that I could have cancer unfortunately, because … I'm still young enough not to have other people relying on me" (Jon, YA) and "… you have that support system … you're still under the wing of your parents" (Sarah, A). This outlook represents an advanced developmental perspective that demonstrates the remarkable strength and resilience of participants toward coping with developmental impacts, as they are able to reflect on both positive and negative aspects of their experience as a young person. These quotes also illustrate the moral and ethical thinking that Erikson understood is pivotal to adolescence (Erikson, 1970b).

Acknowledgement vs. being treated normally

Most participants stated that they did not want to be treated differently, or to be treated in a way that failed to distinguish between themselves as people and cancer. It was important to participants that they were treated as the same person before, during and after treatment. One participant portrayed the people who did not treat her differently as "… the anchors who just didn't change. And everything else did. So it was good to have those people" (Sarah, A). Being treated the same also helped the individual to move away from the ‘sick patient’ role, an important factor when considering AYA identity. Conversely, participants also acknowledged that it was helpful in work, school and social settings, as well as at home, when others treated them with sensitivity towards their health. This was particularly true soon after diagnosis through until treatment concluded, as this was the period where participants tended to be most physically and psychologically vulnerable. The conflict between AYAs wanting to be treated as separate entities to cancer, yet also requiring others to behave considerately towards their situation, was a tension present in most of the participants’ discussions. Sarah (A) illustrated this point by saying, “… they still treated me like I was the same person and, just being treated like I was.. like I wasn’t any different…was really helpful for me.” However she also added, “I don’t really get as many, like, hospital visits… Like they (friends) all made a plan to come and visit me… But they never did… they never really ended up by actually making an effort to do anything for me.”

Peer responses within the school environment were distinctly different from other responses and involved some of the most unhelpful interactions. Staring and inappropriate or hurtful comments were more common for those participants at school, and some participants also commented that their friends stopped inviting them to social events. One participant described this as, “I lost quite a lot of friends cause they’d say they were my friends and then they’d just talk about me behind my back, or be too scared to talk to me” (Emily, A). Older participants (who were not diagnosed whilst in school) tended to be more understanding in their response to others’ reactions and behaviors. This may be partly due to the insight developed in older AYAs, by which a number recognised the difficulty others have with knowing what to do or say, predominantly related to cancer itself rather than themselves personally. Thus, peer responses differed substantially between the younger and older participant groups, and were interpreted differently too, in keeping with developmental stage. Younger adolescents had an egocentric perspective about the impact on them; young adults were able to consider the other’s perspective as well as the effect on them.

Support instead of supporting others

Participants at times distinguished between support received and instances where they were required to support others. Literature has highlighted that survivors can experience overwhelming and distressing emotional reactions from others (Howard et al., 2014; Williamson et al., 2010; Yoo, Aviv, Levine, Ewing, & Au, 2010), a feeling that was also experienced by these AYA participants. Many participants hoped others would be interested to know how they were coping rather than convey their own emotions towards the AYA. One participant disclosed that "nobody actually asked me what I thought of cancer when I got diagnosed" (James, YA), expressing that it is important for family and friends to check how the AYA is and what their thoughts are before responding with their own opinion.

When participants were asked what they would like to change about responses to AYA cancer, it generally revolved around enhancing others' understanding of cancer and the positive prognoses for most. A number of participants commented on the misperception that a cancer diagnosis is a death sentence, and participants indicated that it would "definitely be good for people to understand that (cancer is not a death sentence), to not just hear cancer and automatically assume the worst" (Matthew, YA). The emphasis on others' positivity would enable AYAs to focus on processing their own emotions rather than supporting others with theirs, something young people experiencing cancer may be unable to cope with.

Follow-up interviews (2016)

Twelve months on, two participants had transitioned from high school to university, two had returned to work, and one had transitioned from university to work. Therefore, each of their circumstances had changed since their first interviews, in turn influencing their interactions and the impact of cancer on their development. Upon analysis of the data, three of the above themes appeared to have remained constant, and three themes appeared to change. *Personal privacy and sharing of information* altered substantially for the two participants who were now attending university, as they appeared to struggle with deciding when, how and if to disclose their experience to others. As both these participants were diagnosed in high school, they had lost control of disclosing cancer to others at diagnosis, but at university with a new peer group who were unaware of their health history, they had complete control over sharing this information, which proved to be a daunting experience for these young people - "I don't want it to be like a label... I don't want people to be like 'Oh that's that girl Sarah that I met this year, and she had cancer.' The thing with (hometown) is that people found out whether I wanted them to or not. I'm lucky enough (at University) to have the choice of who I'm telling who I want to tell and have them know exactly what I want them to know, because none of them... knew about it beforehand" (Sarah, A). Two older participants spoke of their newfound comfort speaking with others about their experience, describing this as a way of giving back to others who are in some way affected by cancer. In turn, by sharing their experience they also inadvertently shared the message that cancer was not necessarily a death sentence, and that positive outcomes such as personal growth were also possible.

Independence was no longer such an issue for all participants, as they regained independence from their parents and returned to work or university, or travelled. For example, one participant moved towns to attend University, and one travelled overseas. Changes in independence appeared to occur very quickly over the one year between interviews, a potentially positive sign for some AYAs going forward. It is likely that this increased independence from parents allowed AYAs to work towards establishing their post-cancer identity, especially allowing them to identify more as a young adult rather than a child or adolescent.

Support instead of supporting others also changed, as older participants had a larger capacity to support others, and to give back to others affected by cancer, than when they were interviewed a year earlier - "…if people kind of feel like I've had cancer and that gives them a space to talk about whatever they're going through... I just think it's something.. that I can.. help the world in, I guess" (Jon, YA). Younger participants encountered more support from peers than a year earlier, with new disclosures, and experiencing their peers as more mature at university. These participants were pleasantly surprised at the accepting response others had when they did choose to disclose their experience - "The friends I've made... they didn't know (about cancer), and it didn't... impact the relationship that I made with them, which was really quite cool" (Lisa, A). It may also be likely that the younger AYAs' perception of their peers' responses changed over the one year period, with their increased control over which information their peers were told. Perhaps because their peers were not privy to the high school 'rumour mill', and were more often informed of the cancer by the AYA themselves than their high school peers, their responses (and reflectively, AYAs' positive interpretations of these responses) were more accepting and supportive.

Positivity remained constant as a theme and was ever present for all participants. This related to both participants' own experience of cancer and their outlook on life - "I think you kind of come out of it a stronger person in lots of different ways" (Lisa, A). *Identity formation* – participants appeared to experience the same paradox as was present twelve months previously, where they acknowledged that cancer had contributed to who they were, but it did not define them. Compared with the previous year however, there was less tension between their 'old' and 'new' (post-cancer) selves - "…it's gonna forever be a part of my life. But the fact that people are.. I guess accepting in a way of it, it's... one door closed" (Lisa, A). Lastly, *Acknowledgement versus being treated normally* also stayed constant, as it was still important that cancer was acknowledged, but that participants were still treated normally.

Participants noted that the most helpful aspect of others' responses in the last year was acceptance and coming across as genuine, and acknowledging that cancer was a big part of their lives. However, all follow-up interviews showed an increased emphasis on cancer being slightly in the background rather than the foreground - "…it's kind of in the past, like most people have forgotten about it already" (Sarah, A). Two participants had also lost a close family member since the first interviews, and they reflected on the difficulties of grieving both these deaths and own experiences with cancer - "…coming out of cancer and having (a sudden and unexpected death) all in that same sort of time was quite hard for me back then. But I feel it's really made me stronger now" (James, YA). In addition, one participant also noted his shift in focus from cancer to coping with his family member's death, stating "...the whole, like, dead (family member) thing has kind of replaced cancer, to be honest. Like, it (the death) was kind of the most relevant thing in my life that I openly talk about now" (Jon, YA)). For all participants, cancer continued to inspire their lives and meant they were more appreciative of life in general. Participants also noted increased inner strength, self-awareness, and determination, alongside a strong message of personal strength and growth - "If I'm feeling like, something's really getting me down... I just think... most things would come under cancer. And I'm like well I dealt with that, so..." (Sarah, A).

Discussion

These findings outline the significant impact that cancer has on AYAs in several ways. Firstly, the necessity of two-way communication between AYAs and others is pivotal to ensure the needs of this population are met. Both empowering AYAs and enabling avenues for them to express their needs, as well as providing their support network with communication strategies to best meet their needs, is important. Secondly, the extent to which individual variation occurs in the needs of AYAs is also highlighted, and outlines the need for effective communication pathways for AYAs. It became clear that young people's situations and therefore preferences for communication are unique, and these findings normalise the variability that exists in this respect. Thirdly, interactions that AYAs rated most helpful were those expressing acceptance, empathy and practical and emotional support, whilst interactions involving avoidance and other negative behaviors like staring were reportedly unhelpful. Lastly, this study adds to the evidence demonstrating the substantial impact that cancer has on AYAs' development. This was most impactful on adolescents (aged 16-19), and particularly affected their identity formation.

These findings also suggest that psychosocial interactions, especially those between AYAs and their peers, can affect the incorporation of cancer into the young person's existing identity. This was evident in the general acceptance of cancer in the peer groups of young adults (aged 20-25 years).

It appears that AYAs experience a range of issues related to their psychosocial interactions with others, particularly in the first interviews. This is understandable as AYAs were closer to their diagnostic and treatment experiences when first interviewed. Social and practical support from family, friends and others appears to be immensely beneficial to individuals and their overall outlook on the cancer experience. This reinforces the importance of social support and acceptance for AYAs, and supports the findings of Teall et al. (2013) and Kent et al. (2012). Participants' positive feedback on the support and understanding from others also supports the findings of Zebrack et al. (2010), Williamson et al. (2010), and Tsangaris et al. (2014).

A new finding from the current study is that interactions which convey acceptance, empathy, and understanding and those that provide (or offer to provide) practical and emotional support are most helpful to AYAs. Unsurprisingly, most participants expressed that avoidance and other behaviorally discriminating interactions (such as staring, exclusion and isolation) were largely unhelpful. These initial findings appeared to be reinforced by participants at one year follow-up interviews; fewer unhelpful interactions were reported at follow-up, suggesting either participants had less cancer-related interactions or they interpreted interactions differently as time post-cancer increased. It is also possible that their interactions changed as AYAs' peers matured over a year. Half the participants were lost from the follow-up interviews, however, and this response rate should be considered when interpreting these findings. For example, it might be that those who chose to be involved in the follow-up interviews were managing better than those who did not and this is reflected in their view of the helpfulness of these interactions. This study adds to the literature by identifying that psychosocial interactions, or at least the perception of these, do appear to change over time, and as AYAs and their peers age (particularly with substantial developmental and environmental changes such as beginning university and returning to employment).

It appears that there is some conflict between interactions that endeavour to treat AYAs the same (such as avoiding pity) and those that treat AYAs differently (for instance, inquiring about treatment). This conflict seems to underpin a fundamental tension where AYAs wish to be both acknowledged as strong and invulnerable, and where they hope that others understand the severity of the disease and accommodate their needs. This paradox was also reported by Cantrell and Conte (2009). It is likely that this tension also relates to AYAs' incorporation of cancer within their identities, in the sense that they struggle to include the 'cancer survivor' or 'patient' identity into their previously increasingly autonomous, healthy and perhaps strong selves. After one year the latter tension is less apparent, so it may be that the closer the young person is to their cancer experience, the more relevant this tension is. These results are similar to those of Cantrell and Conte (2009), who reported young adult survivors presented with a paradox of having completed treatment, while cancer still continued to be a part of the individual's identity. This study connects this paradox with the notion that this conflict appears to lessen over time, as AYAs have more time post-treatment and as they and their peers mature. Possibly, as the AYA becomes healthier and experiences fewer physical effects from cancer and its treatment, the young person identifies less with the 'patient' identity and more with the 'survivor' identity. As cancer moves to the background of their focus and re-integration with everyday life continues, they are able to establish their post-cancer identity and what it means for them individually to live beyond cancer. The participant response rate to the follow-up study is also suggestive of participants somewhat moving on from cancer, which fundamentally dominated their lives at the time of the first interviews.

These findings reflect the Children's Oncology Group (COG) survivorship guidelines, which identified the individual's emphasis on placing the cancer diagnosis in the past as a key psychological factor affecting their care (Landier, Hawkins, & Leonard, 2007). Findings from this study that add to the COG guidelines include: the impact on identity formation, difficulties due to increased dependence on parents, developmental conflict, and difficult peer responses. Furthermore, the guidelines recommend parents and survivors be provided with support and education on potential survivorship-related emotional issues, especially concerning the signs of Post-Traumatic Stress Disorder (PTSD), fear of late complications and recurrence, social relationships, and self-esteem or self-confidence issues (Landier et al., 2007). Cancer affects the normal developmental processes that young people experience, and forces AYAs to be faced with discordant developmental issues such as increased dependence. These findings complement those of Dobinson et al. (2016), who identified a developmental regression and identity conflict for some AYAs. They also validate the findings of Stegenga and Macpherson (2014), especially as participants in our study also struggled to incorporate their cancer identity into their pre-cancer identities. Our findings further echoed Stegenga and Macpherson's study in the following ways: highlighting the impact that cancer can have on personal growth; participants' struggles to manage offensive people and those who stare; the physical effects of cancer like hair loss; and the impact that physical effects has on their identity and peer relationships.

Young people's interpretations of psychosocial interactions appear to be related to their developmental stage and how well they are able to understand the world around them. In particular, AYAs' insight and perspective seems to be linked to the number of recalled negative interactions and their developmental stage. Increased insight or perspective might occur as young adults and their peers may become less egocentric in their worldview compared with adolescent AYAs and their peers (Elkind, 1967). The follow-up interview findings support this idea, as younger AYAs find their university peers more supportive than in high school, suggesting increased maturity as their peers transition to young adults. In addition, it should be noted that the young adult participants generally were able to reflect more on their situation at the first interviews than the adolescents did, suggestive of the changes in development as these young people grew (bearing in mind the smaller sample at the follow-up interviews).

These results show that key elements of the developmental process are impacted by cancer, as previously suggested by existing literature (Cantrell & Conte, 2009; Dobinson et al., 2016; Gibbs, 2002; Stegenga & Macpherson, 2014; Williams et al., 2013), although this varies based on factors such as age of diagnosis. This study adds to the literature by identifying that a one year time lapse appears to effect the developmental impact of cancer in a broad sense. This impact lessens or changes its focus as AYAs change environments and transition to young adulthood, or adulthood. These findings illustrate the variability of responses that AYAs experience to their cancer, and their evolving feelings towards their own diagnosis. This indicates that there is no 'right' way for others to respond to this news but rather there needs to be better understanding of how to identify AYAs' individual needs. It also suggests the need for AYAs to learn how to express and communicate their own preferences and needs, and it is the duty of family, friends, and health professionals to facilitate an environment where they are able to do so. The responsibility for effective communication of needs is therefore placed on both AYAs and the groups they interact with.

Clinical Implications

In practice, it is recommended that health professionals discuss the potential responses from others with newly diagnosed AYAs, to work towards preparing them for these reactions and managing their own responses. Clinicians should be aware of the substantial role that development plays in the psychosocial effects on AYAs and factor this in when assessing and treating young people with cancer. Consequently, AYAs should be offered a referral to a mental health or skilled support worker to provide psychological or emotional support and reduce the likelihood of the young person developing ongoing psychological effects from cancer. Furthermore, it is helpful for clinicians to consider taking a systemic approach, by offering to talk to the AYA themselves, and their family, close friends or others about communication strategies and aspects such as privacy and boundaries around information. Involving AYAs in decision making (alongside parents), and keeping them informed of relevant information for their diagnosis and treatment are important for young people to feel respected and valued. In addition, discussing ways to combat disclosure of their cancer to others, and how to cope with social interactions (both positive and negative) *prior to* treatment commencing would be useful for AYAs. COG guidelines also suggest long-term psychological follow up is introduced to the individual and their family prior to treatment commencing (Landier et al., 2007).

Future directions

Future research needs to identify the needs versus experiences of interactions with each of these groups, and to work towards a more comprehensive understanding of how development is impacted by cancer at a young age. Additionally, studies that look at any changes over time in the perspectives of survivors of cancer diagnosed as an AYA would allow researchers to gain a better understanding of how growing older affects the way young people view cancer and the related psychosocial interactions. Future research should assess the psychosocial experiences and needs of a solely Maori and/or Pacific Island population, in order to garner specific information relevant to this population.

Limitations

The small number of participants should be considered when interpreting these results. This number were selected due to the exploratory nature of this study and to establish a sample of AYAs' experiences but it will be important to confirm the findings with a larger sample. In particular, the attrition at the follow-up interviews reduces the generalisability of that part of these findings. Future studies which replicate this research design should aim to recruit more participants, especially to demonstrate the effect of a time lapse. Additionally, nine out of the ten participants were recruited through the support group. It should be considered that the support group provides extensive support to their members and therefore the experiences of AYAs who are not members of a support group may differ. Furthermore, this study was performed in New Zealand, a high income country, and findings may differ in other geographic locations or in low- or middle-income countries.

Conclusions

This study has identified six key psychosocial interaction issues relevant to AYAs with cancer: *Personal privacy and sharing of information*, *Independence*, *Identity formation*, *Positivity*, *Acknowledgement vs. being treated normally*, and *Support instead of supporting others*. It appears that there are common helpful and unhelpful psychosocial interaction types (e.g. acceptance, and avoidance, respectively), although there is some variance of this based on young people's developmental stage. These findings suggest that the meaning and experience of psychosocial interactions from AYAs' perspectives may improve over time, as fewer unhelpful interactions were reported after a one-year time lapse (albeit with a smaller sample size). Therefore communication from others identifying what is helpful or unhelpful for them individually, both during treatment and throughout survivorship, is crucial. There is currently little guidance in New Zealand on how to meet the psychosocial needs of AYAs, and these findings provide the foundations for resources to be formed. It is hoped that these results will assist oncology nurses and others who interact with AYAs to provide beneficial psychosocial support for developmental growth during treatment and throughout survivorship.

Chapter Five

Reflection

As I discussed in the Prologue, I have a personal connection to cancer. Consequently, I felt considerably anxious leading up to the interviewing of participants, particularly with regard to managing any emotional reaction I might have to the content of the interviews, and maintaining a professional boundary. I was also mindful of not wanting participation to have any adverse consequences for the participants through my own personal processes. I assumed that the young people would be somewhat vulnerable and could become emotional when I asked them personal questions. As it turns out, I was wrong to consider participants vulnerable – they demonstrated psychological resiliency and strength, appeared to have excellent coping skills and they were generous with the details that they provided of their experience. I realised it was acceptable to appropriately express my own emotion at times where participants became emotional or shared poignant memories (alongside acknowledging and validating their emotion). I wanted to continue the rapport I had built with the young people by letting them know that I could feel how emotional their stories were too. I felt that this encouraged a human, empathic view of me in their eyes.

Briefly opening up to participants at the beginning of the interview about my experience with cancer was intended to help reduce the power imbalance typical of researchers and participants. While I had wanted to avoid too much sharing of my own experience, all of the participants acknowledged my history when discussing their own – for example, they would say, “Oh, you know what I mean” or “You probably found that too”. As a result, I felt that it was advantageous sharing my experience if it meant that participants could relate to me, and were therefore more forthcoming with their experiences. The more rigid approach I began with in the initial introduction softened as I realised that I could not sit in the room solely as a researcher. My role was two-sided: I wanted to collect data for the purposes of the research but I could not obtain the rich, deeper level content if I did not acknowledge some of my struggles and experiences too. So I interviewed participants as a researcher who has had cancer, a role I felt fulfilled my job to collect data and be ethically responsible for the care of the participants as best as I could.

Hence, before commencing interviews with participants I was conscious of my potential personal reactions to the content of the interviews. Although it is now over ten years since I was diagnosed, my own avoidance of cancer (both outwardly and to a degree, inwardly) was paramount for many years and this resulted in considerable anxiety whenever cancer occurred or was mentioned around me. Writing this thesis on the topic I had been avoiding for around seven years was a turning point because I no longer wanted to ignore such an important time in my life. I could not deny that experiencing cancer had changed me. Thus, I was worried before interviewing participants that this anxiety and avoidance would affect me during the interviews and that I would not be equipped to deal with the emotion in a professional way in front of the participants.

Of course, I discussed this extensively beforehand with my supervisors who were very supportive and who felt confident that I could manage these interviews. In retrospect, given that I had tried so hard to avoid cancer yet it frequently continued to come up in everyday life (in the way of hospital check ups, family/friends experiencing cancer, television shows, etc.) and I had coped, I should have realised that I would work through the emotion in the moment. I had scheduled the first three interviews in one day and after these, even after the first interview, I realised that talking about cancer with these young people would not be as emotionally challenging as I thought it would be. And the confidence that the participants spoke with, their distinct lack of anything shame-related to their experience, reflected back onto me. Therefore, the process of writing a thesis about cancer has become a positive, uplifting experience, where I have learnt a great deal about this topic and the AYA population, and about myself.

Chapter Six

Card-sort Method

The completion of the interviews resulted in a rich source of data for the quantitative research. This chapter begins with an overview of the findings in the Honours model, then outlines the processes involved in recruiting participants, identifying items for the model, and the analyses of the raw data. An explanation of how the data was interpreted is particularly relevant for this study because it involves both quantitative and qualitative interpretation.

Honours model

My Honours research stemmed from an observation that previous literature identified a range of such interactions and their effects, yet no study incorporated all interactions into a complete model (Cameron, 2015). Such a model offers researchers an understanding of what interactions are most beneficial to individuals, and provides a framework for the study of interactions as it shows how they relate to each other. The study identified 74 interactions as a result of the literature search, representative of the concepts and behaviours inherent to interactions between those with cancer and others. The participant sample (n=31) of adults across New Zealand and Australia, grouped these interactions according to the GOPA (Group, Opposite, Partition, Add) sorting method. Hierarchical Custer Analysis (HCA) and Multidimensional Scaling (MDS) were used to form a model in a three-dimensional format, allowing dimensions in the data to be identified, as well as clusters of interactions, and any gaps in the model.

The three dimensions identified in the MDS analysis were Distancing/Avoidance, Support and Attempted Support, along with 13 clusters of interactions. The clusters were labeled: *Discomfort/avoidance*, *Others' experiences, Meaning, Positive/supportive comments, Asks about treatment, Physical changes in PC, Suggestions to help, Negative aspects of cancer, Attributing blame*, *Practical help, Concern for PC's coping, Impact* and *Emotional response*. The study confirmed previous findings of support (both positive and negative) and distancing or avoidance interactions between those with cancer and others. The third dimension, Attempted Support appeared to have been covered less in previous literature than support and distancing or avoidance interactions. This dimension showed that interactions that are perhaps less tactful, but make an attempt to engage with the person with cancer, were grouped together. The distinguishing factor between the Support and Attempted Support dimensions was the latter dimensions' lack of understanding of the disease and its effects, and not knowing what to say or how to support the individual. The Attempted Support dimension indicated the need for education and information about appropriate interactions and general information about diseases, to allow family, friends and others to provide genuine support to the person with cancer, if that is their wish.

A questionnaire was also included for participants to respond to, which aimed to identify the frequency of each interaction being used in a situation involving the participant and a person they may know with cancer. Three clusters - *Concern for PC's coping, Practical help and Impact* - were used most frequently (the frequency of these clusters ranging from 'Quite a lot' to 'A little'), with the remaining ten clusters used infrequently. These results may be subject to the floor effect or the social desirability bias due to the high number of responses involving infrequent interactions. As this was a pilot study, the participant sample was small which limited the variance of responses (particularly for the questionnaire). A number of gaps in the model suggested that some interactions may not yet exist in the literature, or were not identified in the literature search.

AYA model

The Honours model provided relevant findings for the understanding of how adults (who haven't necessarily experienced cancer) view interactions. Applying the existing model to the AYA population provided a valuable opportunity to expand our understanding of how AYAs perceive interactions. To begin with, the sample size and participant inclusion criteria were carefully considered to appropriately represent the population. In order to include relevant interactions from the Honours model to the AYA model, two steps were necessary: firstly, to identify whether the original items were relevant (as these were based on an adult population, and participants were largely non-cancer survivors aged between 16 and 65), and secondly, to include AYA-specific psychosocial interactions derived from interviews with AYAs, to ensure items correctly encompassed the experience of this particular population. To assess the conceptual differences among adolescents and young adults when sorting interactions, we aimed to complete one adolescent and one young adult model, and compare these to better understand developmental differences.

Sample size

In terms of the sample size for a card-sort study, Harloff and Coxon (2007) advise that a stable sorting model usually requires 20-30 participants, Miller (1969) recommends 20 participants, and Nielson (2004) suggests a sample size of 15 to achieve a sufficient correlation of 0.9. Callear, Harvey, and Bimler (2017) created two models of children's emotional regulation for comparison; one model with 30 participants and one model with 29 participants. An MDS map based on the classroom emotional environment by Harvey et al. (2012) involved 33 participants who sorted items for analysis. Therefore we expected that 30 participants in this study was justified by literature in related fields, and that this number was an appropriate target for recruitment within the timeframe available.

Participants

Participants in the card-sort study, as was the case in the qualitative studies, were required to be over 16 years of age, enabling them to give their own consent to be involved in the study. I gathered data on the age of diagnosis for participants but chose to focus the inclusion criteria on the time that had lapsed since participants completed treatment, since treatment for each young person differed and the length of time in treatment was vast for some participants. If I had used the age of diagnosis as an aspect of inclusion criteria instead of time post-treatment, some participants could have experienced cancer a number of years ago, and others very recently. As there are more likely to be more physical difficulties during treatment, it appeared ethically appropriate to gather data from participants at least 6 months after they had completed treatment. The preferred and prioritised time frame for participants was between 6-18 months post-treatment; however, participants up to 3 years post-treatment were included from the beginning due to the overall low numbers in the national AYA population in New Zealand, which contributed to the low response rate and the length of time required to collect sufficient data.

There were ten participants who were included that had experienced treatment more than 3 years ago, and this decision was made on a case-by-case basis in conjunction with my supervisors. As recruitment continued, it became apparent that we were experiencing difficulty finding suitable participants, and consequently, the decision to include a small number of participants who were more than 3 years post-treatment was made. We imposed a limit of the minimum age for cancer diagnosis at the age of 10 when we started to relax the period post-treatment for inclusion, as we felt that young people under age 10 may not remember psychosocial experiences as well, and may have had quite different interactions than those at an adolescent age. This decision is also reflective of the understanding that age 12 is considered an adolescent in New Zealand by AYA standards (Pettit & Watson, 2016).

Identifying interactions for this study

The interactions for the Honours model were identified based on the literature, either where specific examples of interactions were highlighted or based on concepts identified in the literature that related to social interactions between a person with cancer and another. To create the items for the AYA model, following thematic analysis I noted examples of psychosocial interactions or concepts (for example, 'rude comments') from the initial and follow-up interview transcripts. I used these to form a list of AYA-specific interactions. Then I placed this list beside the items from the Honours model, and replaced large portions of the interactions from the Honours model with interactions specific to AYAs. After eliminating all similar or identical interactions the combined list was reduced to 79 interactions. These interactions were placed on item cards for this study. The interactions for this study (applicable only to AYAs**; Appendix G**), and those that were used in the Honours model (that are applicable to the adult population; **Appendix H**) are attached as appendices.

Methodology

Statistical expertise involved in the analysis

Before discussing the methodology involved in this study, it is important to outline the role my supervisor, Dr. David Bimler, had in the analysis of this research. Dr. Bimler conducted the statistical analysis and programming for HCA and MDS, alongside providing guidance on the interpretation of these findings. I was limited in my ability to complete this analysis in conjunction with the qualitative studies. As Dr. Bimler had completed the analysis for my Honours model for the same reason, it appeared logical to involve him to complete this analysis.

The suitability of splitting analysis and interpretation for the model for a DClin thesis is evidenced by the theses of Marwick (2016) and Rosenblatt (2013), which involved Dr. Bimler in the analysis process. Dr. Bimler's role includes the technical stage of feeding the raw data into a programme which informs the similarity matrix, and putting this matrix into SPSS to get the multidimensional scaling. Once I had gathered the data from participants, I sent the raw GOPA results to Dr. Bimler, who used this to create the similarity and dissimilarity matrices, the dendrogram, and completed the analysis for MDS. Dr. Bimler then sent the output of these analyses through to me and I interpreted the findings. I consulted with my supervisors throughout the interpretation, especially Dr. Bimler, whose expertise is in this area. However, I completed the interpretation of the results and the write-up of these.

Methodological description

Further information on GOPA, HCA and MDS processes explain why and how these methods are relevant for this study.

GOPA Task Procedure

Prior to the formation of the GOPA-sorting method, Weller and Romney (1988) identified that data could be easily sorted by participants by creating piles of cards (each with a written or visual stimuli on them) of similar items, and can be constrained by putting a limit on the number of cards per pile, or by asking participants to split piles into further divisions. Since then, Bimler and Kirkland (1998, 2001, 2003) have developed the four-step GOPA (Group, Opposite, Partition and Add) method, which has been successfully applied in past research involving human emotion and interactions. This involves participants forming groups of items that they understand to be similar *(Group)*, ensuring no more than 7 cards belonged in any one group, and between 8 and 16 groups are created. Then participants are asked to find two or three sets of groups that are dissimilar to one another *(Opposite)*. The next phase requires participants to form sub-groups in as many groups as possible, without moving individual items amongst groups *(Partition)*. Both the opposites and partition phases are not expecting participants to complete these in all groups, as some will be too small to separate. Finally, participants are asked to merge groups based on their similarity *(Add)*. There should be at least three mergers; however, some groups may be so dissimilar that they are unable to merge with another group. The task requires participants to record their answers after each step, with the answer sheet providing specific details on how to do this (**Appendix J**).

Hierarchical Cluster Analysis

Analysing the GOPA data involved two distinct processes. Firstly, occurrence data of items in groups must be transformed to co-occurrence data of items, using a similarity matrix. The similarity matrix is used for both HCA and MDS, which are parallel processes. To produce a thorough understanding of the data, Hierarchical Cluster Analysis (HCA) is applied and a dendrogram is produced. The dendrogram is useful for viewing initial clusters, as it displays items in relation to their similarity with other items. Tree-type branches distinguish the similarity of items and group these into clusters, and the height of the branches shared between items represents how similar the items were seen as by the participants. The left-hand side of the dendrogram shows clusters of items, with branches becoming closer together and shorter in length as items increase in similarity. On the right-hand side, items are listed and clusters are identified.

The dendrogram does not distinguish between the most similar or opposing clusters, only between the items. MDS demonstrates the clusters in relation to one another in a spatial format. However the dendrogram is useful for initially identifying clusters and overlaying these on the MDS map to ensure they are cohesive. If cohesion occurs, this indicates the validity of the clusters as most clusters should relate to the dimensions identified by MDS.

Multidimensional Scaling

MDS aims to represent the data as points in a spatial model, or map, resulting in the space between points corresponding as closely as possible to similarities within the actual data (Bimler & Kirkland, 1997). Using both HCA and MDS together has proven to be an effective technique for analyses, as HCA categorises the items and MDS arranges the items dimensionally (Carter, Enyedy, Goodyear, Arcinue, & Puri, 2009). This creates an overlapping effect where the clusters created in the former technique are laid out over the map to show how individuals arrange a number of ideas. Both approaches are used to create a multi-dimensional map of all the items based on their spatial distance or proximity to other items. The map allows researchers to see which items are clustered together – this means those interactions that participants commonly grouped together (or opposite one another).

The map is created by converting the GOPA answers into a table of item-item similarities to establish how often pairs were grouped together. Kruskal (1964) created non-metric MDS algorithms which transforms the similarity values produced from the card-sort into ordinal proximal data, and allows the data to be displayed within a Euclidean space (Marwick, 2016). The algorithms produce values with a range of dimensionality, because each item is placed within the model according to dimensional coordinates (Marwick, 2016). The locations of points in the map are then determined by the goal of getting geometrical distances between them to reflect the corresponding similarities (Bimler & Kirkland, 1997).

MDS has been successfully applied in studies of emotion recognition. Two student's theses that used the MDS method were Rosenblatt (2013) and Marwick (2016), who used this in the study of therapeutic alliance ruptures, in the former study, and the socio-emotional skills of therapists, in the latter study. As a number of studies employing MDS have involved human emotion and interactions, it was deemed a relevant analysis for this research too.

Factor analysis was ruled out as a method of analysis because it examines imperial similarities to items that are rated on a Likert scale (or similar), whereas MDS identifies similarities in conceptual understanding, which was more applicable to our research aims. Furthermore, the small population of AYA in New Zealand means it would have been very difficult to recruit enough participants for factor analysis within the timeframe for a DClin degree. Using MDS meant we were able to foster the exploratory nature of the research by asking participants to group items as they perceived them to be.

Interpretation of HCA and MDS analyses

Analysing this data involved a qualitative and quantitative process; consequently, I employed a number of subjective forms of analysis, through cluster analysis of the dendrogram and map, and semantic map analysis including neighbourhood and dimensional analyses. A split-hemisphere view of the model is attached in the Appendix section to assist with this explanation **(Appendix M).**

Cluster analysis and labeling

Harloff and Coxon (2007) discuss the importance of qualitative interpretation of sorting analysis. For this study that meant labeling clusters and dimensions, as well as part of the decision-making process for the number of dimensions and placement of some items within clusters. After the dendrogram and map were initially formed, I examined the grouping of clusters in each of these analyses to check for consistency and validity across both methods. The clusters identified in the dendrogram were also compared with the map to ascertain the position of a small number of outliers on the dendrogram. Dr. Baken and I discussed which clusters the outliers were closest to and which clusters they appeared to qualitatively fit best with. We then decided which cluster the item best fitted. To ensure validity for the labeling of clusters, we asked a panel of 8 laypeople to label these and then Dr. Baken and I reviewed the responses and decided on the best label based on the most common response from the lay reference group and our opinion based on the cluster content.

Analysis of map dimensions

The dimensions that appear in the map should represent underlying perceptual differences in the data (Rosenblatt, 2013). Dimensions are selected after a number of processes have been completed: the identification of a number of opposing poles in the map, the dimensional weightings, and the meaning of the poles and dimensions. The number of dimensions selected is subjective, but increasing dimensions increases the goodness-of-fit between map distances and the dissimilarities in the data (Bimler & Kirkland, 2001). Previous literature using MDS mapping have found three dimensions produce the optimal and most interpretable model (Callear et al., 2017; Harvey et al., 2012; Marwick, 2016). The researcher makes this decision based on current and past literature, and what makes sense within the data. The ideal number of dimensions can also be described as the configuration of minimum stress (Bimler & Kirkland, 1997; Marwick, 2016). Stress testing showed that three dimensions appeared optimal for this model.

The alignment of the map with the dimensions is then chosen based on what appear to be diametrical opposites. The final alignment is imposed from outside the model, not within it, because rotation does not affect the inter-point distances and it therefore does not impact on the placement of the data (Bimler & Kirkland, 2001). The subjective nature of this decision may be viewed as a limitation of the research, however it is not possible for the alignment to be decided on in any other manner. The map is rotated (based on the meanings associated with the dimensions) until the items or clusters that contributed the most meaning to a dimension and its' extremes are identified as anchors for the axes. At this point the axes can be drawn. The rotation of the map is based on the understanding that the axes intersect at 90 degrees (Rosenblatt, 2013).

There were two clear dimensions from this analysis, and a vaguely identifiable third opposition. When analysing the dimensional weightings I adjusted these to rotate the model and establish how well three dimensions could be interpreted. The first two dimensions that were clearly visible in the model remained constant, and therefore stable, when the model was rotated. The third dimension evident was much less stable, and appeared to be too close to the concepts identified in the first and second dimensions. Therefore we decided to present a three-dimensional model with two-dimensional projections, as the third dimension was present but was unable to be distinguished enough to label. A list of clusters and dimensions is included as **Appendix L**.

Dimensional labels

Once the dimensions were selected, they were labeled based on the clusters encircling the poles (or each end of the dimensions). This process was completed through discussion with my supervisors until consensus was reached on the most suitable labels. Broadly this consisted of examining the labels of the clusters surrounding the poles for each dimension to establish an appropriate label.

Conclusion

In summary, interviewing AYAs was decided to be the most appropriate way to establish which interactions were relevant to this age group, and ensured the interview data analysis was maximized (as interviews were required for the earlier study). A multidimensional model, similar to the Honours model but applicable to AYAs, was chosen as it provides information on the relationship between items. The Group, Opposite, Partition, Add (GOPA) card-sort method has successfully worked with human emotion studies previously, and is analysed by Hierarchical Cluster Analysis (HCA) and Multidimensional Scaling (MDS) to form a multidimensional model of interactions. HCA is used to identify approximate clusters of items through the use of a dendrogram analysis, while MDS allows the data to be viewed as a multidimensional map, enabling dimensions in the data to be recognised and clusters initially identified by HCA to be confirmed. As a result, dimensions and a number of clusters of interactions within the model should be identified at the conclusion of analyses. This explanation of methods employed in the card-sort task should provide the reader with an understanding of why these methods were selected and how the model is constructed. The following chapter includes the details of the card-sort study, presented as a journal article. The manuscript has been submitted to the Journal of Cancer Survivorship for publication.

Chapter Seven

Introduction to quantitative study

The following article is based on the quantitative part of this thesis. That is, asking participants to sort interactions, which are used to form a multidimensional model. This study has been reviewed and approved by the Central Health and Disability Ethics Committee New Zealand on the 8th June 2016 based on the expedited review pathway – application 16/CEN/54.

The following article has been submitted to the Journal of Cancer Survivorship in March 2019.

A model of psychosocial interactions of Adolescents and Young Adult (AYA) cancer survivors

Background

The psychosocial impact of cancer on a young person can have particularly significant consequences because of the vulnerabilities associated with their developmental stage. Erikson proposed that adolescence and young adulthood are times where young people contemplate morality, ethical thinking, and identity formation, which can all be complicated by a cancer diagnosis (Erikson, 1970b; Kivnick & Wells, 2014). The impact of cancer on AYAs range from increased risk of psychosocial distress and the development of mood disorders (Lang et al., 2018), to the impact of social support on treatment adherence, which in turn might affect short- and long-term health outcomes (McGrady et al., 2016). Psychosocial issues applicable to AYA survivors have been proven to be specific to this age group, and separate from issues facing children and adults (D'Agostino, Penney, & Zebrack, 2011; Richter et al., 2015). The psychosocial interactions that AYAs experience with their family, friends and others can have a profound impact on their experience with cancer, from diagnosis through to survivorship.

Social support

Psychosocial interactions can be related to social support, which is a broad and encompassing term with a number of connotations. Shumaker and Brownell (1984) define social support as “an exchange of resources between at least two individuals perceived by the provider or the recipient to be intended to enhance the well-being of the recipient” (p. 13). Social support, for the purposes of this study, is assumed to be favourably interpreted by the receiver unless it is specifically described as negative.

Studies often show that AYAs are receiving social support with both positive and negative effects. A study by Zebrack, Chesler and Kaplan (2010) looked at communications and behaviours that were helpful and hurtful for AYA, to identify their effect on the physical and emotional well-being of young people. They found that ‘positive attention’, ‘the promotion of normal life’ and ‘other survivors’ were considered helpful whereas ‘negative or lack of attention’, and ‘denying or dismissing experience’ were believed to be unhelpful. Unhelpful behaviours included being ignored or avoided, behaviours that denied or dismissed their experiences (such as being patronized), verbal suggestions of incompetence, parental over-protectiveness and inappropriate comments. Overall the AYA participants stated the importance of interpersonal support, suggesting that social support - and negative behaviours - can significantly impact their experience with cancer (Zebrack et al., 2010).

Research shows that social support, particularly from family and peers, is immensely important for AYAs (Breuer et al., 2017), and can have many benefits, such as stronger relationships (Bellizzi et al., 2012) and increased appreciation for family (Lehmann et al., 2014), and positive affect in young people (Wesley et al., 2013). Despite this, the usefulness of support from friends and peers often varies. While friendships that existed prior to the cancer diagnosis can be very helpful for AYAs, the developmental stage typical of adolescents can hinder their understanding and compassion for peers with cancer (Wakefield et al., 2013). Evan and Zeltzer (2006) and Zebrack (2011) suggest that the type of social support sought by a young person with cancer is likely to depend on the age of the individual and their peers.

Social support from other AYAs can also be an important source of support. A study by Love et al. (2012) examined the psychosocial support offered in an AYA online support group and found that informational and emotional support were the most prominent themes amongst discussions. This study found that members of the online group differentiated strongly between those within the group – fellow cancer survivors – and those who have not experienced cancer themselves. Previous literature has well documented the value of social support from fellow cancer survivors for AYAs (Goldfarb & Casillas, 2014; Stegenga, 2014; Thompson et al., 2009).

Social Interactions

Research has identified that AYAs can benefit from talking about cancer with their support network regardless of whether they have experienced a positive or negative impact on their relationships following their diagnosis (Kent et al., 2013). Kent et al. (2013) noted the importance of teaching AYAs effective ways to communicate their experiences and emotions with their families and friends. Furthermore, Barnett, Shuk, Conway, and Ford (2014) asked AYAs about their experiences disclosing their cancer to others, and found that responses depended on the person's age. For instance, younger people tended to respond with surprise, shock or immaturity, whereas older people were less surprised, and more interested and understanding when discussing cancer (Barnett et al., 2016). AYAs in this study reported that positive interactions around disclosure were helpful and comforting, which attests to the importance of identifying ways to encourage more positive interactions for AYAs when discussing their cancer.

A study by Bonanno and Esmaeli (2012) looking at interactions between facially disfigured individuals and both acquaintances and strangers identified three distinct patterns of interactions. These included: intrusion, by asking unsolicited questions; sympathy, involving unwanted actions aimed to help; and benign neglect, where the person receives no particular attention to their disfigurement (Bonanno & Esmaeli, 2012). Breuer et al. (2017) identified in their study of YA cancer survivors, two-thirds of YAs experienced negative interactions, largely with friends who became avoidant over the course of their illness. Other unhelpful interactions mentioned by YAs in this study included feeling misunderstood during conversations, others expressing their discomfort with mortality or cancer in general, and avoidance of cancer by pretending it did not exist (Breuer et al., 2017). Whether they are intentional or not, interactions which the individual perceives as negative can cause them distress and further discomfort (Blanchard et al., 1995).

The original model/gaps in existing research

The research discussed thus far addressed some of the psychosocial interactions that AYAs encounter, or the reactions and responses of others toward these individuals and cancer. Although there are several models of social interactions applicable to other fields, such as social anxiety (Goldfried, Padawer, & Robins, 1984) and teachers' social networks (Moolenaar, Sleegers, Karsten, & Daly, 2012), to the best of our knowledge there is no existing model that identifies an accumulation of interactions relevant to AYA cancer survivors. The closest model identified pertaining to AYAs is a concept map of AYAs' survivorship needs by Hydeman (2019), in which psychosocial concerns are included. However, that model had a broad focus on survivorship challenges and did not focus on sorting psychosocial interactions specifically. In addition, a study conducted by Cameron (2015) created a model with an adult sample, which incorporated a comprehensive range of interactions between people with cancer and others. This model drew the psychosocial interactions from the literature and used a three-dimensional analysis technique to identify 13 clusters of similar interactions. These included: *Discomfort/avoidance, Others' experiences, Meaning, Positive/supportive comments, Asks about treatment, Physical changes in Person with Cancer, Suggestions to help, Negative aspects of cancer, Attributing blame, Practical help, Concern for Person with Cancer's coping, Impact* and *Emotional response*. These findings were interesting but were limited by not being organised by cancer survivors and focused on adults rather than AYAs. To apply this model to the AYA group it needs to be re-modelled to ensure that it appropriately applies to this population.

The present study

This study aims to understand the relationships between psychosocial interactions for AYAs, by asking AYA cancer survivors to organise interactions into similar or opposing groups. To address the AYA experience with cancer from a broad perspective, we have chosen to research how AYAs (aged 16-25 years) perceive the relationships between social interactions. This involves asking participants (n=30;

AYA cancer survivors) to complete a GOPA (Group, Opposite, Partition and Add) card-sort task. This study aims to provide a comprehensive model of interactions that are appropriate to the AYA age group.

Method

Item formation

Interviews by Cameron, Ross, Baken, and Bimler (In Press) with ten AYAs (aged between 16-25) took place in 2015. Psychosocial interactions mentioned by participants were identified and then compared with the interactions from the Cameron's (2015) original model so that similar or identical interactions could be removed and the best description of the interaction identified. A large portion of the interactions from the original model were replaced with interactions taken from AYAs' interview transcripts as they better represented the AYA experience. After eliminating all similar or identical interactions the list was reduced to 79 interactions. The first author initially completed the process of eliminating interactions and deciding on the final list, and then the second author checked these for reliability. Once consensus was reached, interactions were written as brief statements that captured the essence of the concept, in third person form. Interactions were then placed on item cards for participants.

Participants

Inclusion criteria for participation were: aged between 16-25, diagnosed with cancer after the age of 10, at least six months post-treatment, no current severe mental health issues, and no ongoing cognitive effects from cancer or treatment that would interfere with the task. Inclusion criteria were discussed via email with interested AYAs, and those who indicated that they were experiencing mental health or cognitive effects were asked to elaborate. A description of what participants were required to do for the task was supplied to AYAs and they were asked whether they felt their mental health would worsen, or whether their cognitive effects would make the task more difficult. If AYAs who reported mental health issues felt they were able to participate we checked if they had supports in place and were under mental health or counselling guidance before including them. The final decision to include or exclude participants was made by the second and fourth authors, who are both senior clinical psychologists.

Recruitment of participants began in June 2016 and finished in October 2018. Participants were recruited through CanTeen New Zealand (a non-profit organisation supporting young people with cancer), and through a national press release. Forty-one participant packs were sent out to interested AYAs, and thirty packs were returned. Participants were aged between 16-26 (the 26 year olds agreed to participate when they were 25, but had turned 26 by the time their participant pack was returned), and their overall mean age was 20.8 years. One participant provided no identifying information, therefore participant information is based on 29 participants. Twenty-five participants were CanTeen members. Five participants were male, and 24 participants were female. Ethnic groups of participants are described in Table 1. Table 2 describes the participants' cancer type. Most participants were affected by either lymphoma or leukemia, which is in line with research findings for common AYA cancers. Participants were provided with a $20 supermarket gift voucher upon completion of the task.

Table 1. *Ethnic make-up of participants.*

Ethnicity	Participants
New Zealand European	20
New Zealand European/Maori	2
New Zealand European/Japanese	1
New Zealand European/Thai	1
Maori	1
Chinese	1
Samoan	1
British	1

Caucasian	1

Table 2. *Participants' cancer type.*

Cancer type	Participants affected
Hodgkins Lymphoma	10
Acute Lymphoblastic Leukemia	3
Acute myeloid leukemia	3
Non-Hodgkins Lymphoma	2
Osteosarcoma	2
Ovarian	2
Brain tumour	2
Other	5

Materials

Participants were provided with an information and instruction sheet, a consent form, and an answer sheet (for the GOPA responses). They were also given a set of 79 cards measuring 5cmx4cm each with one of the 79 items printed on to be used for the GOPA-sorting process. Step-by-step instructions were provided for the card-sort task that was replicated from a similar study by Rosenblatt (2013).

Group, Opposite, Partition, Add (GOPA) task procedure

Participants used the GOPA (Group, Opposite, Partition, Add) procedure to sort the cards. This approach was designed to identify perceived similarities and differences among participant's conceptualisations of items and has been successfully applied in past research involving human emotion and interactions (Bimler & Kirkland, 1997, 1998, 2001, 2003). The Grouping phase involved forming groups of similar items, where between 8 and 16 groups were created. Then participants were asked to find two or three sets of opposing groups (Opposite phase). The Partition phase required participants to form sub-groups in as many of the original groups as possible, without moving individual items amongst groups. Both the Opposite and Partition phases were not expecting participants to complete these in all groups, as some will not be an extreme opposite of another group, or will be too small to partition. Finally, similar groups were merged based on their similarity (Add phase). The task required participants to record their answers after each step, and the answer sheet provided specific details on how to do this. The sample size of thirty was sufficiently large for statistical purposes (Harloff & Coxon, 2007; Miller, 1969; Nielson, 2004).

Analysis

Similarity values were generated for each item in relation to each other item. Similarity was represented numerically with a number from 0 through to 1 where 0 represented no similarity (never placed in the same group even after merging groups) to 1 (always placed in the same group even after partitioning). The similarity values were identified for each pairing and placed in a 79 x 79 matrix, which was used by both the HCA and MDS analysis. Analysing the GOPA data involved two distinct processes. Firstly, Hierarchical Cluster Analysis (HCA) was applied and secondly, Multidimensional Scaling (MDS) was utilised, and the results from both approaches were combined to understand the data. These two approaches have proven to be complementary when used together, as HCA categorises the items and MDS arranges the items dimensionally (Carter et al., 2009). This creates an overlapping effect where the clusters created in the former technique are laid out over the map to show how individuals arrange a number of ideas. Both approaches are used to create a three-dimensional map of all the items based where the spatial distance between items represents the perceived similarity of the items. The number of item clusters (i.e. where to cut the dendrogram into branches) is based on the dendrogram and the positioning of items in the MDS model, however ultimately this is a qualitative process as the researchers decide the ‘goodness of fit’ for each item within a cluster. Items that appear to be in a cluster on the model or dendrogram but do not make sense when combined with other items in that cluster can be placed in another cluster with which the items seem more semantically aligned.

Reliability

Reliability procedures included the first and second author examining the MDS model and dendrogram to decide on each item's 'goodness of fit' until both authors felt comfortable with the placement of each item. A small number of items were shifted after this process following consultation with the fourth author, whose expertise is in MDS modelling. These authors decided on preliminary names for the clusters, and then asked a group of 8 people (a combination of mental health workers, clinical psychologists and laypeople) to label clusters. The first, second, and fourth authors then deliberated the names of each cluster, considering all 8 responses plus the authors' preliminary labels until consensus was reached. Dimensions were also labelled through deliberation by the same authors until consensus was reached.

Results

Raw data

Nine participants omitted some of the items when recording group membership on their GOPA response form; this does not affect how their responses contribute to the similarity values for other items.

Hierarchical Cluster Analysis (HCA)

A dendrogram is useful for viewing initial clusters as it displays items in relation to their similarity with other items. Tree-type branches distinguish the similarity of items and group these into clusters, and the length of the branches shared between items represents how similar the items were seen as by the participants (the shorter the branch, the more similarity exists between items). Figure 1 displays the dendrogram, with preliminary clusters identified and labeled. The left-hand side of the dendrogram shows clusters of items, with branches becoming closer together and shorter in length as items increase in similarity. On the right-hand side, items are listed and clusters are identified.

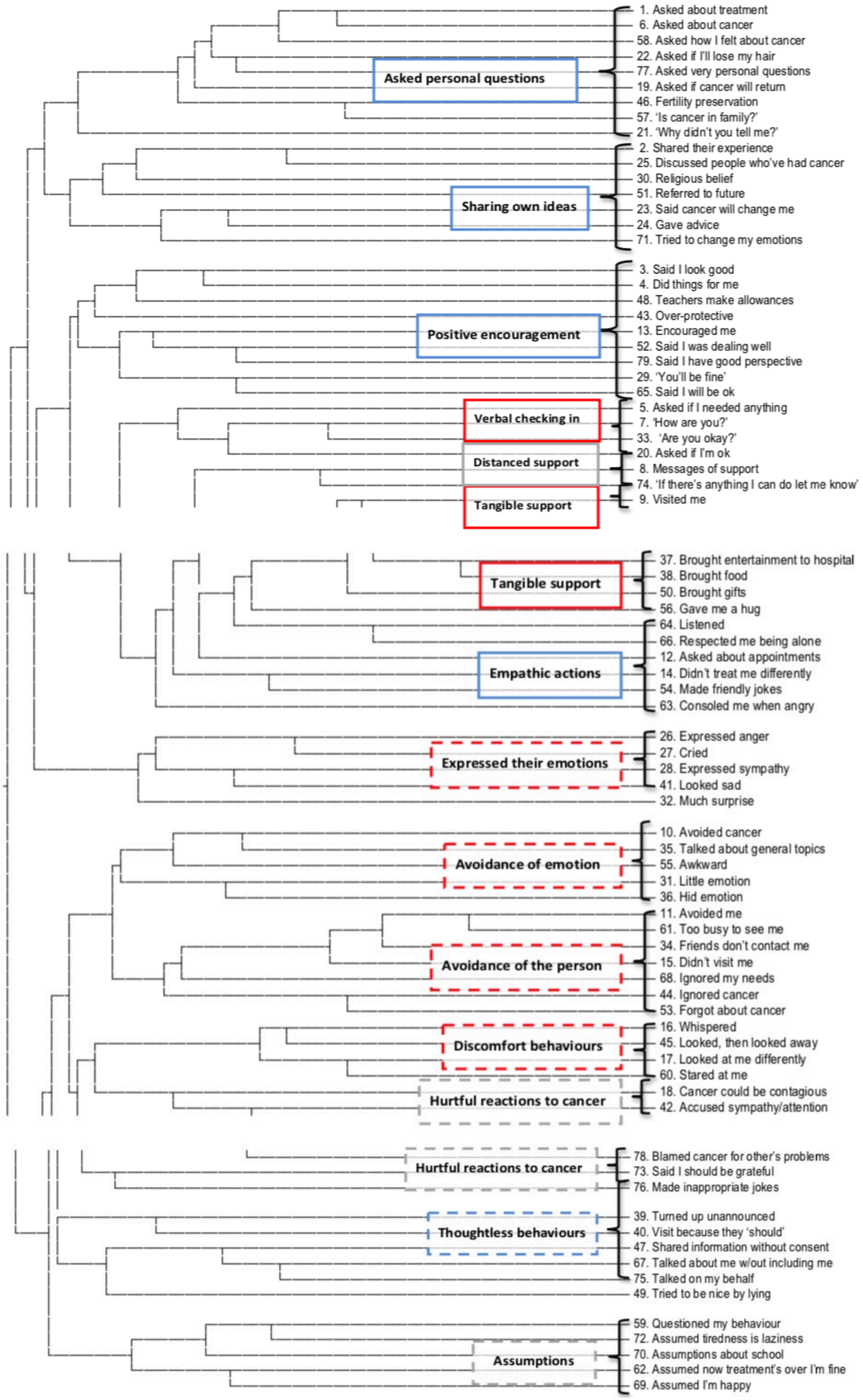

1. Asked about treatment
6. Asked about cancer
58. Asked how I felt about cancer
22. Asked if I'll lose my hair
Asked personal questions
77. Asked very personal questions
19. Asked if cancer will return
46. Fertility preservation
57. 'Is cancer in family?'
21. 'Why didn't you tell me?'
2. Shared their experience
25. Discussed people who've had cancer
30. Religious belief
51. Referred to future
Sharing own ideas
23. Said cancer will change me
24. Gave advice
71. Tried to change my emotions
3. Said I look good
4. Did things for me
48. Teachers make allowances
43. Over-protective
Positive encouragement
13. Encouraged me
52. Said I was dealing well
79. Said I have good perspective
29. 'You'll be fine'
65. Said I will be ok
Verbal checking in
5. Asked if I needed anything
7. 'How are you?'
33. 'Are you okay?'
Distanced support
20. Asked if I'm ok
8. Messages of support
74. 'If there's anything I can do let me know'
Tangible support
9. Visited me
37. Brought entertainment to hospital
Tangible support
38. Brought food
50. Brought gifts
56. Gave me a hug
64. Listened
66. Respected me being alone
12. Asked about appointments
Empathic actions
14. Didn't treat me differently
54. Made friendly jokes
63. Consoled me when angry
26. Expressed anger
27. Cried
Expressed their emotions
28. Expressed sympathy
41. Looked sad
32. Much surprise
10. Avoided cancer
35. Talked about general topics
Avoidance of emotion
55. Awkward
31. Little emotion
36. Hid emotion
11. Avoided me
61. Too busy to see me
34. Friends don't contact me
Avoidance of the person
15. Didn't visit me
68. Ignored my needs
44. Ignored cancer
53. Forgot about cancer
16. Whispered
Discomfort behaviours
45. Looked, then looked away
17. Looked at me differently
60. Stared at me
Hurtful reactions to cancer
18. Cancer could be contagious
42. Accused sympathy/attention
78. Blamed cancer for other's problems
Hurtful reactions to cancer
73. Said I should be grateful
76. Made inappropriate jokes
39. Turned up unannounced
Thoughtless behaviours
40. Visit because they 'should'
47. Shared information without consent
67. Talked about me w/out including me
75. Talked on my behalf
49. Tried to be nice by lying
59. Questioned my behaviour
72. Assumed tiredness is laziness
70. Assumptions about school
Assumptions
62. Assumed now treatment's over I'm fine
69. Assumed I'm happy

Figure 1. Dendrogram with item numbers and descriptions, and cluster labels. Coloured lines around each cluster name correspond to the shapes representing each cluster in Figures 2 and 3. Solid lines correspond to a solid shape and dotted lines correspond to a hollow shape.

All 79 items belong to a cluster, although some were outliers of clusters and were then included in the most similar cluster. There were 14 clusters identified through the dendrogram, which were then taken forward to the MDS stage. These clusters were named: *Asked personal questions, Sharing own ideas, Positive encouragement, Verbal checking in, Distanced support, Tangible support, Empathic actions, Expressed their emotions, Avoidance of emotion, Avoidance of the person, Discomfort behaviours, Hurtful reactions to cancer, Thoughtless behaviours, and Assumptions.*

Multidimensional Scaling (MDS)

Two dimensions were identified in this model, although other conceptual oppositions are visible but are not orthogonal to the two identified dimensions, and therefore cannot be treated as independent axes themselves. The dimensions reflect the 'working model' in each participant's mind, or the way that they conceptualized each item as related to the others. Dimension X was labelled *Emotional Response*, consisting of two opposing poles: *Avoidance/Discomfort* and *Support*. Dimension Y was labelled *Empathy*, and consisted of the opposing poles: *Empathic actions/Encouragement*, and *Thoughtlessness*. Figures 2 and 3 show split-hemisphere views of the model, where shapes and colours of the symbols indicate their clusters in the Figure 1.

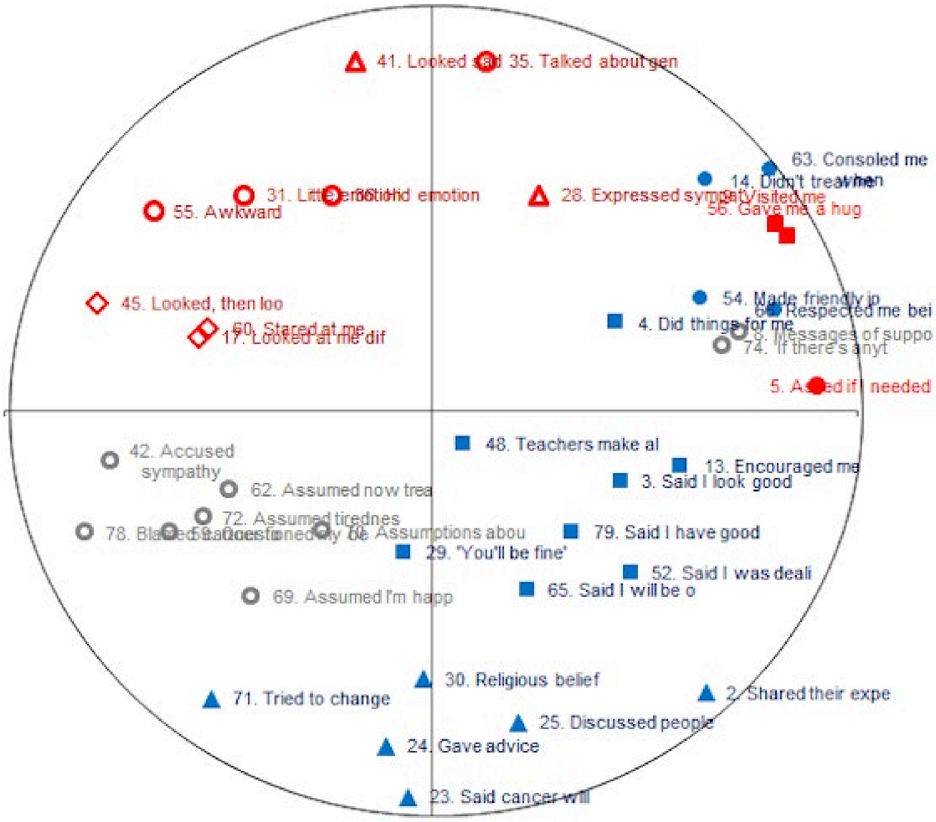


Figure 2. Split-hemisphere view of model shows the *Emotional Response* (red symbols) and *Empathy* (blue symbols) dimensions. Grey items do not relate to either dimension. Solid blue squares= *Verbal encouragement* cluster, solid blue triangles= *Sharing own ideas*, solid blue circles= *Empathic actions*. Hollow blue circles= *Thoughtless behaviours* cluster, hollow blue squares= *Asked personal questions*. Solid red circles= *Verbal checking in* cluster, solid red squares= *Tangible support*. Hollow red circles= *Avoidance of emotion* cluster, hollow red squares= *Avoidance of the person*, hollow red diamonds= *Discomfort behaviours*, hollow red triangles= *Expressed their emotions*.

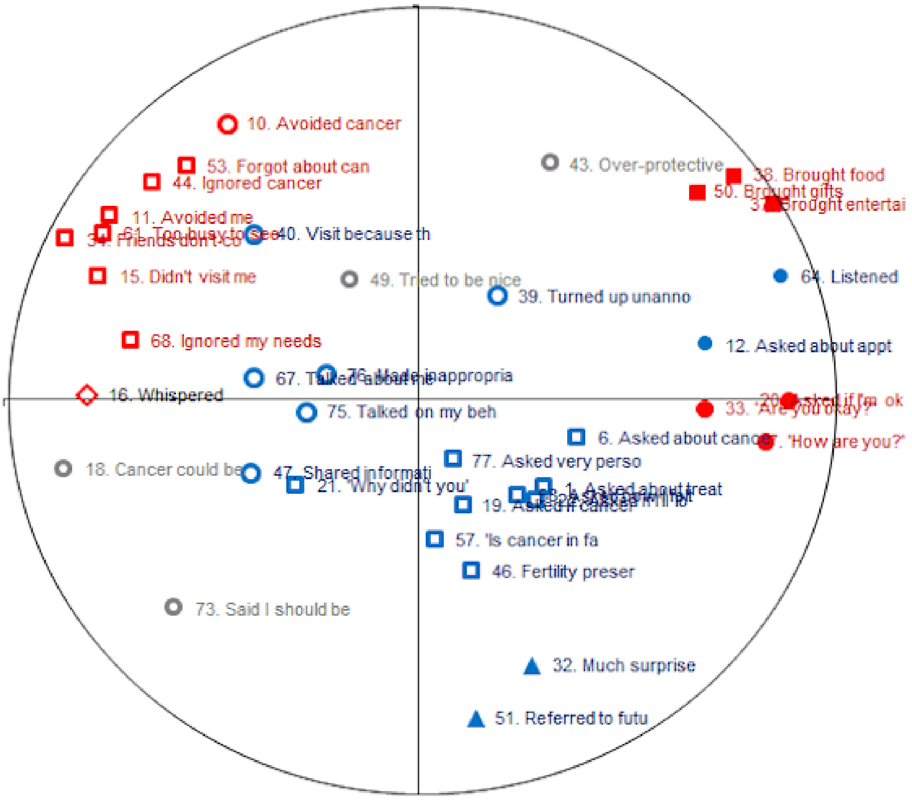


Figure 3. Split-hemisphere view of model shows the *Emotional Response* (red symbols) and *Empathy* (blue symbols) dimensions. Grey items do not relate to either dimension. Solid blue squares= *Verbal encouragement* cluster, solid blue triangles= *Sharing own ideas*, solid blue circles= *Empathic actions*. Hollow blue circles= *Thoughtless behaviours* cluster, hollow blue squares= *Asked personal questions*. Solid red circles= *Verbal checking in* cluster, solid red squares= *Tangible support*. Hollow red circles= *Avoidance of emotion* cluster, hollow red squares= *Avoidance of the person*, hollow red diamonds= *Discomfort behaviours*, hollow red triangles= *Expressed their emotions*.

The MDS map was then examined to identify whether clusters in the dendrogram also appeared in the model. Dendrogram clusters remained coherent in the model, although two items were closer to a different cluster on the map than their locations in the dendrogram, and were shifted accordingly. Poles do not necessarily link to direct clusters of items as they are conceptual ideals, however Table 3 lists the clusters surrounding each pole to assist with demonstrating why each dimension and pole are labelled as they are.

Table 3. *MDS Model and Clusters*

Dimensions	**Poles**	**Clusters surrounding poles**
X: Emotional response	Avoidance/Discomfort	Avoidance of the emotion Avoidance of the person Discomfort behaviours Expressed their emotions
	Support	Verbal checking in Tangible support
Y: Empathy	Empathic actions/ Encouragement	Empathic actions Verbal encouragement Sharing own ideas
	Thoughtlessness	Thoughtless behaviours Asked personal questions

Gaps identified in the model

Two gaps can be seen in the split-hemisphere view of the model in Figures 2 and 3. A gap in Figure 2 sits between the *Expressed their emotions* cluster (red-coloured triangle outlines), the *Discomfort/Avoidance* pole (red-coloured diamond, circle and triangle outlines) and the *Assumptions* cluster (grey circle outlines). In Figure 3 is a gap between the *Support* pole (red coloured-in squares and circles), the *Avoidance/Discomfort* pole (red-coloured square, circle and diamond outlines) and the *Thoughtless behaviours* cluster (blue-coloured circle outlines).

Discussion

A total of 79 interactions were identified in the literature and derived from interviews as representative of behaviours or concepts inherent to psychosocial interactions between AYAs and others. Hierarchical Cluster Analysis (HCA) was used to identify initial clusters of items by identifying the relationships among them as a dendrogram. Multidimensional Scaling (MDS) allowed the data to be viewed as a multidimensional map, enabled clusters initially identified by HCA to be confirmed and dimensions in the data to be recognised. As a result of the HCA and MDS analyses, 14 clusters of interactions and two dimensions were identified.

The validity of these clusters was supported by their presence in both the dendrogram (in the HCA analysis) and in the MDS model. There appears to be a range of interactions between these clusters, from supportive types (e.g. *Positive encouragement, Empathic actions, Tangible support*) to somewhat less-encouraging types (e.g*. Hurtful reactions to cancer, Discomfort behaviours, Thoughtless behaviours*). A number of clusters excluding these two types were also present. For instance, *Asked personal questions* and *Sharing own ideas* are relevant to the person with cancer's health and situation without necessarily being either supportive or less encouraging. Natural responses, such as *Expressed their emotions* are understandable interactions. Therefore, the clusters cover a wide range of interactions, from perhaps more common interactions to those less common. Of particular interest are the way participants have organised items in Dimension X: *Emotional Response*. The *Expressed their emotions* cluster is grouped near *Avoidance* and *Discomfort* clusters, suggesting participants associate the emotional expression as being unhelpful interactions. In addition, the pole labelled *Thoughtlessness* under the *Empathy* dimension contains the cluster *Asked personal questions*. This is grouped close to the *Thoughtless behaviours* cluster, suggesting participants perceive personal questions as potentially ignorant and asked without consideration of the AYAs' feelings or situation. However, the *Sharing own ideas* cluster is grouped alongside *Empathic actions* and *Verbal encouragement* (in the *Empathic Actions/Encouragement* pole).

Also, a number of these clusters have been identified as groups of interactions in the original model created by Cameron (2015). For instance, *Discomfort/Avoidance, Others' experiences, Positive/supportive comments, Practical help, Emotional response, Asks about treatment, Attributing blame, Suggestions to help,* and *Negative aspects of cancer* all very closely align with clusters in this model. The *Emotional Response* dimension in this study also aligns closely with the findings in the adult model, as the dimensions in that study were labelled *Distancing/Avoidance, Support* and *Attempted Support* (Cameron, 2015). This further validates the findings of this model as similar clusters have been identified in previous research.

Of some interest are the discrepancies between the findings of this model and those of the interview results by Cameron et al. (In Press). Cameron et al. (In Press) found participants welcomed carefully timed and sensitive questions rather than entertaining assumptions or rumours, whereas in the current model participants have grouped the more generic and potentially invasive interactions in the *Asked personal questions* cluster close to *Thoughtless behaviours*. Furthermore, *Sharing ideas* is grouped near empathic actions and encouragement items in the model, however participants in the study by Cameron et al. (In Press) largely preferred not to hear others' ideas or experiences. This could be due to a bigger sample size in the current research, and with a larger sample size comes a bigger number of experiences. It may also relate to the way participants were asked about their experiences: in the interviews AYAs were asked directly about their own experiences, and in this card-sort study participants were asked to sort interactions written in third person tense. Using the third person tense provides some disconnect between participants' personal experiences and experiences that could include both their own and other AYAs' interactions too.

Distancing and avoidance interactions (similar to those addressed in this study) have been identified in previous literature involving AYA and adult cancer survivors (Bonanno & Esmaeli, 2012; Breuer et al., 2017; Zebrack et al., 2010). Zebrack et al.

(2010) identified ignorance or avoidance interactions as unhelpful, while Breuer et al. (2017) found YAs noted pretending cancer did not exist and expressing discomfort with cancer in general was unhelpful. This is reflected in the responses of the participants in the current study who grouped together interactions related to *Discomfort behaviours, Avoidance of the person* and *Avoidance of emotion.* To further contribute to distancing and avoidance interactions, AYAs may be more prone to experiencing these as cancer treatment can result in lengthy absences from educational and social attendances (Howard et al., 2014). However AYAs in previous studies have discussed the importance of being treated normally as if they do not have cancer (Cameron et al., In Press; Zebrack et al., 2010), and this could be perceived by AYAs as avoidance if their peers do not address cancer.

Bonanno and Esmaeli (2012) described interactions that participants found intrusive, notably by asking unwelcome or inappropriate questions. This is similar to the *Asked personal questions* cluster in this model. Many previous studies have identified that offering practical or emotional support is useful for AYAs (Breuer et al., 2017; Love et al., 2012; Wakefield et al., 2013), and this is reflected in our model where participants have grouped items such as *Verbal checking in* and *Tangible support* together. Emotional expression has also been identified in the literature, particularly the emotional reaction when AYAs disclose their cancer diagnosis (Barnett et al., 2016). Overall, a range of interactions grouped together by AYAs in this study has already been described by other AYAs previously.

However, the multi-dimensional nature of the model also enabled a number of relatively small holes to be identified. When gaps exist within the model, this indicates that an area is missing from the literature (because it does not yet exist), the literature search was incomplete, or the interaction was not mentioned in the interviews. The first gap sits between the *Support* and *Avoidance/Discomfort* poles, and the *Thoughtless behaviours* cluster. Perhaps this suggests that interactions where there is social obligation involved may be initiated with good intentions but lack the support that AYA personally needs. The second gap is located between the

Discomfort/Avoidance pole, *Expressed their emotions* and *Assumptions* clusters. This could suggest emotion tailored to the AYA and the appropriate situation is missing, as the emotional expression interactions that exist are placed close to the *Distancing* and *Avoidance* clusters. A future study could test the hypotheses suggested for missing interactions, along with validating this model.

This study adds to the literature in a number of ways. Firstly, this research is the only organised sorting of interactions by AYAs themselves that the authors are aware of. This means that no other model of interactions for AYAs, sorted by AYAs, exists. These findings provide information on how these interactions are organised and perceived by young people. Specifically, this study indicates that AYAs organise most interactions by two ways: the emotional response of the other person, and the empathy (or lack of empathy) involved in the interaction. Secondly, very little research has been done in New Zealand for this population. Therefore, this study adds to our knowledge of the psychosocial interactions of AYAs in New Zealand.

Limitations

A limitation of the brief items used to describe interactions is the possibility of alternative interpretations or multiple ideas implicit within one item, for example, in the *Asked personal questions* cluster participants may have assumed these questions were asked sensitively, or that they were posed by someone who the young person was comfortable with asking that question. Consequently items themselves are limited to the brevity that suited the overall design of the model. The relatively small participant sample is a limitation and therefore this study should be validated on a larger scale, and with other ethnic populations to compare results. Females heavily dominated the participant sample, therefore these findings are limited in their generalisability to both sexes. Future research should focus on a more even gender sample. It is imperative that these results be interpreted on the basis of their grounding in the New Zealand population – the same interactions may not occur or be represented the same in another study using a different population. Furthermore, this sample largely consists of CanTeen members, whose experiences may be different to AYAs who were not members of a large support network. This study should be replicated with a sample of both CanTeen and non-CanTeen members to ensure results are applicable to both groups.

Conclusion/Future Directions

The GOPA similarity sorting method required thirty AYA participants to sort item cards describing various interactions between an AYA and another person. HCA and MDS analysis produced a multidimensional model that demonstrated the collated conceptual similarity sorting of items. Two dimensions (*Emotional Response* and *Empathy*) and 14 clusters of interactions were identified, suggesting participants approximately sorted items into those categories. Ideally, future research should seek to replicate this study with a different sample of participants, to ensure that the results generalise. It is also necessary to review the gaps present in this model and examine what knowledge may be missing from the current literature. Filling these gaps would enable the model to be complete and more useful when applied in other projects. Secondly, it would be useful to ask AYAs what interactions are helpful and unhelpful in a systematic and categorical way, to better understand how to improve effective communication between the AYA and their support network.

In future it would be useful to separate the participant sample into adolescent and young adult groups to establish whether there are sorting differences when accounting for developmental stage. In terms of clinical implications, it is important that clinicians working with AYAs assist young people with adjusting their expectations of others’ responses to cancer. Working with AYAs alongside their support network will likely be the most effective way to resolve communication issues and provide a safe space for young people to express their needs and communication preferences. It is hoped that educating individuals using these findings will reduce the negative social interactions for young people affected by cancer.

Chapter Eight

Reflection

The completion of the model of psychosocial interactions allows all of the pieces of this study to come together. The interpretation of the model continues in the Discussion chapter that follows; however as this thesis is a mixed-methods study, it seems appropriate to include a self-reflection at this stage too.

The completion of the model signifies just over two years of recruiting the 30 required participants for the study – no small feat! Close to the end of recruitment two of my close relatives were diagnosed with cancer. This was the first time since I had been diagnosed that I was faced with confronting someone else's diagnosis. The news of both these diagnoses occurred in the same week, which felt like a particularly brutal blow. Sitting on the 'other' side of the cancer fence – where I was the responder in these interactions instead of the patient – had its' own challenges for me. My first thoughts when I was given this news were based on responding in the most appropriate way. I quickly tried to think through the 'helpful' responses to being told about a cancer diagnosis, and what young people had said was the best or most appropriate response. I realised how difficult it actually is to be put on the spot and try to say the 'right' thing. I also realised that these two different people had their own very different responses to their diagnoses. One was considering their own mortality, and the other remained optimistic about their prognosis. My response was different to both of those because I considered their diagnosis in light of my own experience, and my relationship to these people. What would it mean for me if cancer took them from this world?

These two varying experiences with both relatives taught me that researching psychosocial interactions, interviewing AYAs about which responses are helpful or unhelpful, and even experiencing cancer myself could not provide me with an instantly appropriate response. There is no ‘perfect’ response. Everyone struggles with this. The most appropriate response for one person is different to another, and we do not have the ability to predict what that might be. When it comes to cancer, we all feel helpless, and we all struggle to find the right words to express our feelings. This put into context some of the participants’ experiences with friends or family who did not respond in the way that they needed. I came to understand that being that family member or friend is really hard too – they just do not necessarily know what to say or how to say it. If I have studied this topic for years and been in the AYAs’ shoes and I still do not know what to say, how would others?

I have tried to keep this frame of mind when writing the Discussion chapter, because regardless of how interactions cluster and dimensions form in the model, these are human responses in a really difficult scenario. At the end of the day, we are only human and we make mistakes, or sometimes words do not come out in the way we intended them to. My positioning as a researcher and an AYA cancer survivor has also extended during the research to being the relative of someone who has cancer, and I feel that trifold positioning gives me an understanding of what cancer is like from a number of different perspectives. This does influence how I have written the final study (the model of interactions), and the Discussion chapter, and perhaps I have expressed others’ responses in a more empathic way than I otherwise would have. Now that I know how difficult it can be when you’re on the receiving end of that disclosure, I have consciously tried to be more understanding of the recipients’ in these interactions. And maybe the most appropriate response we can give others who disclose their cancer diagnosis is our expression of love and sorrow, in whatever way is most accessible and kindest to ourselves.

Chapter Nine

Discussion

"I always remember this one other CanTeen member… her saying was, "Look forward to looking back." And that stuck with me throughout this whole thing."

- *Hannah*

This thesis aimed to explore the psychosocial interactions specific to young people with cancer in New Zealand. Developmental stage was also explored; both by investigating how developmental stage may have influenced young people's perception of interactions, and by looking at whether the impact of their developmental stage changed over time. To answer this, ten interviews were conducted with AYAs in 2015 and five follow up interviews took place a year after. The interactions identified in the initial interviews were then amalgamated with relevant interactions ascertained in a similar existing model with an adult population, and the combined list was sorted into similar and opposing groups by thirty AYAs. This sorting process resulted in a multidimensional model of interactions, which allowed for an understanding of how young people with cancer perceive the relationship between these interactions. Overall, this research provides an in-depth exploration into the psychosocial interactions of AYAs in New Zealand, as well as the relationship between time, developmental stage and their psychosocial experiences. This chapter summarises the findings of the qualitative and quantitative research, followed by a discussion of how these studies fit with one another, how this research contributes to the body of knowledge on AYAs, research limitations and what gaps need to be addressed in future research. Self-reflections are included throughout the chapter as a continuation of the reflection that has occurred in previous chapters.

Interviews

The initial interviews were conducted with AYA participants (n=10) to explore helpful or unhelpful psychosocial interactions and the relationship between experiencing cancer and the development of these young people. Follow-up interviews provided a one-year longitudinal understanding of AYAs psychosocial interactions and the possible impact on their development. The initial interviews occurred in 2015; the follow-up interviews in 2016 aimed to identify whether time or age effects AYAs psychosocial interactions, or perception of these interactions, and whether a one-year time period (encompassing important transitions for many of the participants) affects the developmental impact on these young people. The follow-up interviews yielded a fifty percent response rate – five participants from the initial interviews.

The results from this study identified a range of themes including: the importance of personal privacy and controlled sharing of information, independence, identity formation, positivity, acknowledgement of cancer vs. being treated normally, and receiving support instead of supporting others. In the one year follow-up interviews, half of these themes remained constant; however the personal privacy, independence and supporting others themes changed. Overall, social support, psychosocial interactions and developmental stage appear to influence the overall cancer experience. Development appears to be impacted by cancer for both adolescents and young adults, but this impact lessened over a one-year period.

We aimed to explore whether previous findings fit with the participants' experiences in this study. Existing research findings were largely supported – participants did rate distancing, obtrusive or inappropriate questioning, staring and being treated differently as unhelpful. These findings support those of previous research (Flanagan & Holmes, 2000; Zebrack et al., 2010). Further unhelpful interactions identified in this research included privacy breaches, other people expressing their own emotion rather than prioritizing the AYAs' feelings, exclusion and isolation. Helpful interactions did include listening alongside the conveyance of acceptance, empathy and understanding – similar to the findings of Teall et al. (2013) and Kent et al. (2012) - however participants did not discuss practical help in-depth.

Being treated as the same person they were pre-cancer was discussed as helpful but AYAs also acknowledged that it was helpful for others to recognise their cancer – ignoring cancer completely was described by some participants as unhelpful. Most did appreciate, however, being treated as the same person throughout diagnosis and treatment which Iannarino et al. (2017) also identified. The same difficulties were discussed in relation to being treated differently: participants wanted their cancer to be acknowledged and whilst they did not expect special treatment, it was appreciated when others accommodated their changing needs (such as providing food in hospital or understanding why they could not attend school or social events). This paradox has been discussed previously by Cantrell and Conte (2009). Lastly, participants did identify developmental disruptions across both age groups, consistent with previous literature (Cantrell & Conte, 2009; Dobinson et al., 2016; Gibbs, 2002; Stegenga & Macpherson, 2014; Williams et al., 2013). However, while Gibbs (2002) found AYAs were often embroiled in earlier developmental conflicts, this was not true for the majority of participants in this study. Most were concerned with many of the same developmental conflicts as their friends, such as identity formation, but their identity concerns directly related to cancer (as concerns surrounded amputation, hair loss, or scarring etc.). If anything, participants in this study did not regress developmentally, but some may have skipped ahead of their peers to concerns about their fertility and/or mortality.

Adolescent participants experienced more difficulty relating to peers than young adults did. Schooling disruptions were also more common in younger participants, partly due to adolescents attending school (whereas young adults were working or attending University). However, young people at University were able to put their study on hold without consequences, whereas adolescents who were delayed in schoolwork felt the effects of being ‘left behind’ the rest of the class. It may be possible that adolescents also felt pressure from school to keep up with schoolwork to avoid repeating their year, which could have had profound educational and social effects.

Most participants discussed a change in their perspective since experiencing cancer. Some reported posttraumatic growth, as previously identified by Zebrack et al. (2015), whilst others noted increased positivity and appreciation for life. However, unlike Stegenga and Macpherson (2014), whose participants noted their cancer experience had resulted in reduced family conflict, and struggled significantly with their loss of hair, participants in this study did not discuss hair loss at length - although one male participant said he had received some hurtful comments regarding his bald head. This may be due to participants receiving cancer treatment that did not result in hair loss. Participants also did not mention family conflict as a result of cancer, instead discussing how cancer had created more family unity.

It is important to note that despite the proportion of Maori and Pacific Island participants (60%) in the initial interviews, participants did not discuss the cultural relevance of cancer for themselves or their families. This was true across both interview time points. While this was surprising, it may reflect my own ethnic background as a New Zealand European researcher, which means I may have missed cultural references or not invited these discussions in the way that a Maori or Pacific Island researcher might have. Alternatively, the lack of discussion about culture may suggest there are commonalities in the impact of cancer across AYAs from difference cultural backgrounds in New Zealand. Unfortunately there is an absence of research in this area in New Zealand, which highlights the importance of future studies.

The interviews were my first opportunity to speak with AYAs since I had experienced cancer, and this was a profound personal experience for me. Despite much anxiety about how I would cope emotionally, I found the acceptance and insight of the participants comforting. Their rationality of the situation reflected on to me and I was able to focus on their stories more and more as the interviews continued. As I discussed in the self-reflection chapter following on from the interviews, participants frequently mentioned our shared experience when telling me about various interactions. This provided a connection between us that reduced the researcher and participant power imbalance. It should also be acknowledged that at times participants made reference to our shared experience (for instance, some said “you know what I mean”), which may have led to aspects of our conversation going unspoken. It may be possible that participants would not have gone into as much detail with another researcher who had not experienced cancer as an AYA. I wholeheartedly believe that this connection strengthened the research overall and encouraged AYAs to share their experiences in a safe and empathic environment.

Card-sort

The interviews also aimed to identify psychosocial interactions relevant to young people that are not already present in the existing model. The research question specific to item formation asked: what psychosocial interactions do AYAs encounter in their experience with cancer? To answer this, the interactions talked about by AYAs in the interviews were combined with relevant interactions from the Honours model. The list of AYA items (**Appendix G**) and the items from the Honours model (**Appendix H**) are listed in the Appendices chapter. The card-sort used the same methodology as the Honours model to create a multidimensional model of interactions relevant for AYAs. The dendrogram tree of interactions resulting from Hierarchical Cluster Analysis (HCA) and the split-hemisphere views of the model are listed as **Appendix’s K** and **M**, respectively.

Two dimensions (Emotional Response and Empathy) were identified within the model. The dimension Emotional Response displayed two opposing poles: Avoidance/Discomfort and Support Interactions. The Empathy dimension comprised of Empathic Actions/Encouragement and Thoughtlessness Oppositions. In addition, 14 clusters of interactions were identified: Asked personal questions, Sharing own ideas, Positive encouragement, Verbal checking in, Distanced support, Tangible support, Empathic actions, Expressed their emotions, Avoidance of emotion, Avoidance of the person, Discomfort behaviours, Hurtful reactions to cancer, Thoughtless behaviours, and Assumptions. The grouping of interactions in the model highlights the nature of individual preferences for responses, as the placement of items in the model suggests how close or far apart participants as a group perceived interactions to be. For instance, the *Sharing own ideas* cluster is grouped alongside *Empathic actions* and *Verbal encouragement* clusters, which suggests perhaps participants perceive someone sharing their own ideas to be a supportive interaction - given the literature and the interview findings report AYAs find empathic actions helpful. However, in the interviews many participants discussed their frustration with other people sharing their own ideas, as some felt others' ideas and experiences were not relevant for them individually.

In the planning phase we had intended to complete two models for comparison of age groups among the sorting of interactions. This was important because the interviews identified the differences experienced by adolescents and young adults. However, after a number of processes were explored, it was established that it was not statistically possible with the sample size we had to produce two meaningful models. To begin with we looked at the difference between participants rather than the difference between items. This involved placing individual sorting matrices into SPSS to establish whether a single spatial model of sorting occurred between age groups. Unfortunately SPSS didn't tolerate any missing data (of which there was some) in this analysis, and therefore it was unable to be completed. Dr. Bimler then tried to analyse a single similarity matrix using factor analysis, and this showed a large first factor (likely the first dimension), however we were unable to identify any statistically significant differences between participants' responses. Thus, the analysis of responses between age groups was not possible as the systematic difference between groups was not obvious. The comparison of models for the two age groups would be a useful addition to the literature for future research.

The findings of the AYA model are in accordance with previous literature, including the identification of distancing and avoidance interactions by Bonanno and Esmaeli (2012); Breuer et al. (2017); Zebrack et al. (2010). Existing studies have also demonstrated the helpfulness of practical and emotional support for AYAs (Breuer et al., 2017; Love et al., 2012; Wakefield et al., 2013), as well as the emotional reaction AYAs face when disclosing their diagnosis (Barnett et al., 2016). The findings of this research therefore confirm those of previous literature, where similar interactions have been grouped and labelled for the AYA population. Furthermore, this model is the first study we are aware of where AYAs have organised interactions into groups themselves, unlike a study by Zebrack et al. (2010) where researchers organised the interactions instead.

The results from the Honours model also identified Support and Distancing/Avoidance dimensions. The *Emotional Response* dimension in the AYA model closely aligns with the findings in the Honours model, as the dimensions in that study were labelled Distancing/Avoidance, Support and Attempted Support. The *Emotional Response* dimension contains poles labelled *Discomfort/Avoidance*, and *Support,* and many of the items in this dimension are similar to the Distancing/Avoidance, Support and Attempted Support items in the Honours model. There were also a number of similar clusters identified in the adult and AYA models (although some are worded slightly differently), including: Discomfort/Avoidance, Others' experiences, Positive/supportive comments, Practical help, Emotional response, Asks about treatment, Attributing blame, Suggestions to help, and Negative aspects of cancer all very closely align with clusters in the AYA model. These similar clusters and dimensions indicate consistency between the findings of the AYA, and the Honours models. This also confirmed the hypothesis that there would be similar results in this model as the Honours study, for both clusters and Support and Distancing/Avoidance dimensions.

What both studies' findings tell us

The completed model, in conjunction with the interview findings, enhances our understanding of the relationship between interactions that young people experience. A thorough understanding of these interactions, and how AYAs perceive them in relation to each other, is pivotal to our knowledge of the psychosocial impact that interactions have on AYAs.

Both studies' findings indicate the separation of supportive and unsupportive interaction types, which has been clearly described by previous literature (Bonanno & Esmaeli, 2012; Breuer et al., 2017; Zebrack et al., 2010). The interview findings suggested AYAs face a variety of responses to cancer, which resulted in a range of interactions for AYAs to sort in the model. This variability of reactions and emotions that others portray has been discussed in existing research (Barnett et al., 2016; Iannarino et al., 2017). This research supports the findings of previous studies discussing AYAs preferences for certain responses, particularly emotional and tangible support (Iannarino et al., 2017; Kent et al., 2012), interactions which AYAs grouped together in the model. Unfortunately, while it was not possible to compare adolescent and young adult differences in the sorting of interactions, the qualitative studies did demonstrate that key aspects of the developmental process are affected by cancer. The extent of this effect appeared to lessen over a one-year time period. Both studies provide an idea of how young people with cancer in New Zealand experience and perceive psychosocial interactions, which attempts to fill a gap in current literature.

Additionally, combining the qualitative and quantitative findings means we are able to understand the range of helpful and unhelpful interactions when they are organised into dimensions. We can align these groups with what AYAs reported were helpful and unhelpful interactions from the interviews, to better understand what a larger number of AYAs view as supportive interaction types. Most young people in the interviews described the Support pole interactions (*Verbal checking in* and *Tangible support* clusters) as helpful, as well as some of the clusters in the *Empathic actions/Verbal encouragement* pole – with the exception of the *Sharing own ideas* cluster. Most interview participants also described the *Avoidance/Discomfort* pole interactions as unhelpful, as were the *Thoughtless behaviours* cluster interactions.

Interestingly, some discrepancies arose between the findings of the model and the interviews. The interview results found participants invited carefully timed and sensitive questions rather than hearing assumptions or rumours, whereas in the model participants have grouped *'Asked personal questions'* close to *'Thoughtless behaviours'*. This suggests that consensus from card-sort participants was that personal questions were intrusive and unwelcome. Furthermore, *'Sharing ideas'* is grouped near empathic actions and encouragement items in the model; however participants in the interviews largely preferred not to hear others' ideas or experiences. It is important to acknowledge here that grouping items close to another in the model implies that they are perceived as similar by participants; however, it is the researcher's interpretation (and assumptions) of these placements that suggests participants view these interactions as helpful or unhelpful.

These discrepancies between study findings could be attributed to a bigger sample size in the card-sort study, alongside a wider range of experiences. It may also relate to the way participants were asked about their experiences: in the interviews AYAs were asked directly about their own experiences, and in the card-sort study participants were asked to sort interactions written in third person tense. Furthermore, the nature of qualitative research enabled the young people who were interviewed to describe their interactions in context of certain relationships and circumstances; however the card-sort task did not accommodate for this type of information. The nature of sorting interactions using the GOPA method is much more black-and-white. A limitation of the HCA and MDS analyses is the placement of interactions in the final model are collective responses, and do not represent each participant's responses. Whilst there is no clear cut 'helpful' and 'unhelpful' way to interact with AYAs (because their needs and preferences are individual and may change constantly), having a better understanding of what is perceived to be more or less helpful on a larger scale can provide a basis for deciphering how to best support these young people.

What is new or different about this research?

This study is the first research in New Zealand to examine the psychosocial interactions of AYA cancer survivors and the relationship with their development. There is very little research conducted using solely New Zealand AYA participants, so we consider this an exciting step forward in our knowledge of the psychosocial cancer experience in New Zealand's youth. Furthermore, there are few studies that explore the longitudinal impact of cancer on the ordinary development of this population. As we have demonstrated, this is a valuable perspective because AYAs can be experiencing different developmental stages, and cancer impacted these participants differently after one year.

There is also relatively little emotion identification research that exists on the AYA population. The model contributes to the literature by identifying not only emotions and interactions, but also an understanding of the underlying perceptual differences between these by exploring how participants organise and understand interactions (i.e. by emotional response and empathy). This provides knowledge on a comprehensive list of possible interactions and where AYAs place interactions in relation to each other.

Complementing the findings of the AYA model with the Honours model (based on an adult population) provides a more comprehensive multidimensional model of cancer-specific psychosocial interactions. Furthermore, the adult model is specific to Australasia, and the AYA model is specific to New Zealand, which provides some information on how adults and young people respectively view these experiences.

However, the Honours model is based on an adult population who have not experienced cancer, whereas the AYA model uses a sample of young people who have experienced cancer.

Finally, this may be the first research in New Zealand on AYAs by a cancer survivor. There is likely plenty of international research by AYA survivors; however of the little New Zealand research, none (as far as I am aware) has been conducted by a survivor. As mentioned earlier, this adds an element of empathy and understanding to qualitative research that is difficult to replicate without this shared experience between researcher and participants. Furthermore, the relationships built with service providers like CanTeen - who were essential for participant recruitment - were perhaps stronger because they were aware of my personal involvement in this research.

Limitations and future research

As has previously been discussed, the participants in both studies were largely recruited through CanTeen New Zealand. CanTeen members are offered substantial peer and professional support throughout their cancer journey, and experiences of non-CanTeen members may differ. It should also be acknowledged that only a portion of AYAs join CanTeen, and those who do join might fit a similar personality profile to AYAs who are not members. Furthermore, it may be possible that the onus on 'giving back' to the AYA population by participating in research was a motivating and encouraging factor for participants, especially CanTeen members. Replicating these studies with a non-CanTeen population is the only way to know if the additional supports offered through this support network affect psychosocial experiences and potentially influence developmental impact.

A limitation of the model is its' lack of accountability for developmental differences. This disrupted the story carried through the interviews of the developmental impact of cancer on young people. Regrettably we were unable to obtain enough data to clearly separate the adolescent and young adult findings. The minimum number of participants for the GOPA analysis to function is thirty, which took just over eighteen months to gather. Data collection only ceased due to time constraints in writing and submitting this thesis. In future it would be useful to separate the participant sample into adolescent and young adult groups to establish whether there are sorting differences when considering developmental stage. In addition, it would be useful to add to the findings of the model by asking AYAs how often they experienced these interactions and how helpful they found them. This information would complement the overall story of this research, and would have been included if the research scope was larger.

The participant sample in both studies was small (although reflective of the New Zealand AYA population size), and replication both studies with larger samples would be beneficial for continuing to build our knowledge. Similarly, as the participant sample was solely New Zealand based these results can only be generalised to the New Zealand AYA population. Replication of this research in other countries is required to generalise the findings to other nationalities and ethnicities.

Future research should examine risk factors that have an impact on AYAs psychosocial experience, such as fertility. AYAs and their families may undervalue the risk to fertility at the time of treatment, but could affect young people significantly as they enter survivorship. In addition, it would be valuable to know whether fertility preservation options are offered in practice in New Zealand, and how to best improve these efforts in the event that they are not satisfactorily discussed (from the AYAs' perspective). Fertility issues or infertility, among other late effects resulting from cancer treatment, can further disrupt the developmental progression of young people.

It may be considered a strength or a limitation that my experience as an AYA cancer survivor permeates the findings of this research, to some degree or another. While this is explicitly discussed in connecting chapters throughout the thesis, it is likely to have affected both qualitative and quantitative studies through a number of means. For example, highlighting certain literature, paying more or less attention to various themes or findings, and through the interpretation of those findings. My supervisors' advice and opinions on drafts may have mediated this effect; however, my personal experience should still be considered when examining these findings. It may be considered a strength in terms of relating to participants in the interviews and potentially drawing out more information from young people. I was aware when beginning this research that I would need to be very conscious of over-stepping a personal and professional boundary (because I could relate to AYAs personally and transparently), and through extensive discussion in supervision I understand this was largely avoided. Despite being aware that my experience likely affects the way I have conducted my research, I do not believe this has been to its' detriment.

Where to from here?

Using these findings to create resources for the family and friends of AYAs to advise them on the psychosocial experiences of AYAs may be beneficial as a precursor to the issues their loved one may experience, or as a problem-solving tool. Such a resource would not aim to advise readers on what to say or what to not say (as this research has shown that AYAs needs and wants vary and can change regularly), but it could highlight what is generally helpful or unhelpful, and how to facilitate an environment where they can communicate with the AYA to best understand their evolving needs. A similar resource could be created for AYAs to provide tips for communicating their needs effectively.

In addition, small workshops run for AYAs and their friends and family may be beneficial for teaching both parties how to openly communicate with each other, with the goal of best supporting each others' needs. As Stegenga and Macpherson (2014) advise, aiming to intervene with only an adolescent or a parent is unlikely to be successful due to the joint task of granting and gaining independence. Workshops for health professionals could focus on the developmental impact that cancer can have on AYAs and how to minimise this impact. This could benefit treatment adherence if AYAs feel they are valued and respected. Furthermore, it can be a delicate balance between accommodating AYAs' wishes and those of their families. Providing health professionals with tools for mediation and achieving unity among the family unit may be useful.

Overall, literature on the AYA population has moved forward substantially in the past fifteen years. We now know much more about the psychosocial and developmental impact of cancer. However, up until now there has been little research on AYAs in New Zealand, few insights into the developmental impact using a longitudinal design, and no organised sorting of interactions by AYAs themselves. This research adds to the existing body of knowledge in this respect. There is still much more to learn though, and the second half of this chapter outlines some of the gaps that remain in our knowledge in the psychosocial field of AYA cancer. It is hoped that we will continue to see the dedication to research with this population in the years to come, as much more research is still required.

Chapter Ten

Conclusion

"Being able to stand in the rubble of what was once your life and kind of grow from there... it's hard but it'll serve everyone that's gone through it well"

– Jon

This thesis details the relationship between the psychosocial interactions of AYA cancer survivors and the impact on their development. A review of existing literature on this topic demonstrated the need to examine this relationship with a New Zealand population. To thoroughly understand this relationship, a mixed methods approach was undertaken. Qualitative interviews asked participants to describe interactions and how these affected their development. One year follow-up interviews showed that the impact of cancer changes over a one-year period, which was possibly due to development. The interviews provided a range of interactions that AYAs encounter, and showed a clear influence on the development of young people. Preferences for others' responses varied to an extent, based on the needs of the young person at the time, although AYAs clearly identified some universally helpful and unhelpful interactions. The developmental consequences were more pronounced for adolescents than young adults, likely due to their peers' maturity, secure peer networks and a clearer sense of self for older participants.

A quantitative study followed which involved asking thirty AYAs to sort interactions using a GOPA card-sort process, resulting in a multidimensional model of interactions. This model showed that AYAs conceptualise interactions in two main ways: through their perception of emotional response (avoidance/discomfort and support interactions) and empathy (empathic actions/encouragement and thoughtlessness interactions). Unfortunately the sample size was too small to complete two separate models comparing age differences, and therefore an understanding of developmental disparities in conceptualising interactions was unable to occur.

Overall, these two studies provide an understanding of how AYAs in New Zealand perceive and respond to psychosocial interactions. Furthermore, there is an enhanced understanding of the developmental consequences for young people with cancer. Follow-up interviews allowed for a unique insight into how the developmental impact changed over a one-year time period, and how this differed for adolescents and young adults. The research findings highlight the individual nature of social expectations and needs when a young person faces cancer.

As those needs are ever changing, going forward it is important that AYAs and their support networks work together to clearly communicate young people's needs, so that family and friends are able to meet these needs. This research proudly contributes to the body of knowledge on AYAs in New Zealand, their psychosocial needs and the way cancer impacts on their development. Cancer is a cruel disease that takes away many things, but it can eventuate in improved relationships when the support network is able to meet the young persons' needs.

References

Anazodo, A., & Chard, J. (2013). Medical and psychosocial challenges in caring for adolescent and young adult patients with cancer. *CancerForum, 37*(1), 23-26.

Andrykowski, M. A., Lykins, E., & Floyd, A. (2008). Psychological health in cancer survivors. *Seminars in Oncology Nursing, 24*(3), 193-201. doi:10.1016/j.soncn.2008.05.007

AYA Cancer Network. (2017). Retrieved from https://ayacancernetwork.org.nz/standardofcare

Ballantine, K., & Sullivan, M. (2013). *Adolescent and young adult cancer incidence and survival in New Zealand 2000-2009*. Retrieved from Auckland, New Zealand:

Barnett, M., McDonnell, G., DeRosa, A., Schuler, T., Philip, E., Peterson, L., . . . Ford, J. S. (2016). Psychosocial outcomes and interventions among cancer survivors diagnosed during adolescence and young adulthood (AYA): a systematic review. *Journal of Cancer Survivorship, 10*(5), 814-831. doi:10.1007/s11764-016-0527-6

Barnett, M., Shuk, E. M., Conway, F. P., & Ford, J. S. (2014). Cancer-Related Disclosure Among Adolescent and Young Adult Cancer Survivors: A Qualitative Study. *Journal of Adolescent and Young Adult Oncology, 3*(3), 123-129. doi:10.1089/jayao.2013.0043

Bellizzi, K. M., Smith, A., Schmidt, S., Keegan, T. H., Zebrack, B., Lynch, C. F., . . . Patient Experience Study Collaborative, G. (2012). Positive and negative psychosocial impact of being diagnosed with cancer as an adolescent or young adult. *Cancer, 118*(20), 5155-5162. doi:10.1002/cncr.27512

Bimler, D., & Kirkland, J. (1997). Multidimensional scaling of hierarchical sorting data applied to facial expressions. *Scandinavian Journal of Psychology, 38*, 349-357.

Bimler, D., & Kirkland, J. (1998). Perceptual modelling of product similarities using sorting data. *Marketing Bulletin, 9*, 16-27.

Bimler, D., & Kirkland, J. (2001). Categorical perception of facial expressions of emotion: evidence from multidimensional scaling. *Cognition and Emotion, 15*(5), 633-658.

Bimler, D., & Kirkland, J. (2003). Smoke and mirrors: mapping the dimensions of a 'cigarette space'. *Quality and Quantity, 37*(4), 377-391.

Bjornsen, C. A. (2000). The blessing as a rite of passage in adolescence. *Adolescence, 35*(138), 357-363.

Blanchard, C. G., Albrecht, T. L., Ruckdeschel, J. C., Grant, C. H., & Hemmick, R. M. (1995). The Role of Social Support in Adaptation to Cancer and to Survival. *Journal of Psychosocial Oncology, 13*(1-2), 75-95. doi:10.1300/j077v13n01_05

Bleyer, A. (2007). Young adult oncology: the patients and their survival challenges. *CA: A Cancer Journal for Clinicians, 57*, 242-255.

Blos, P. (1985). *Son and father: Before and beyond the Oedipus complex*. New York: The Free Press.

Bonanno, A., & Esmaeli, B. (2012). Facial Disfigurement, Stigma, and Cancer: Interaction Between Patients and Members of Secondary Groups. *Sociological Spectrum, 32*(2), 138-156. doi:10.1080/02732173.2012.646156

Bradbeer, P., & Ballantine, K. (2015). *NZCCR Report 2015*. Retrieved from Auckland, New Zealand: http://childcancernetwork.org.nz/wp-content/uploads/2016/04/NZCCR-Report-20151.pdf

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101.

Breuer, N., Sender, A., Daneck, L., Mentschke, L., Leuteritz, K., Friedrich, M., . . . Geue, K. (2017). How do young adults with cancer perceive social support? A qualitative study. *Journal of Psychosocial Oncology, 35*(3), 292-308. doi:10.1080/07347332.2017.1289290

Brunet, J., Love, C., Ramphal, R., & Sabiston, C. M. (2014). Stress and physical activity: the moderating role of social support. *Support Care Cancer, 22*, 689-695. doi:10.1007/s00520-013-2023-0

Burr, V. (2006). *An introduction to social constructionism*: Routledge.

Callear, A., Harvey, S. T., & Bimler, D. (2017). Understanding the structure of children's emotion-regulation strategies. *International Journal of Behavioral Development, 41*(3), 456-462.

Cameron, N. (2015). *A model of interactions of people with cancer* (Honours). Massey University,

Cameron, N., Ross, K., Baken, D., & Bimler, D. (In Press). The psychosocial interactions of Adolescents and Young Adult (AYA) cancer survivors and the possible relationship with their development. *Cancer Nursing*.

Cantrell, M. A., & Conte, T. M. (2009). Between being cured and being healed: the paradox of childhood cancer survivorship. *Qualitative health research, 19*(3), 312-322. doi:10.1177/1049732308330467

Carlsson, A. A., Kihlgren, A., & Sorlie, V. (2008). Embodied suffering: experiences of fear in adolescent girls with cancer. *Journal of Child Health Care, 12*(2), 129-143. doi:10.1177/1367493508088550

Carter, J. W., Enyedy, K. C., Goodyear, R. K., Arcinue, F., & Puri, N. N. (2009). Concept mapping of the events supervisees find helpful in group supervision. *Training and Education in Professional Psychology, 3*(1), 1-9. doi:10.1037/a0013656

Corey, A. L., Haase, J. E., Azzouz, F., & Monahan, P. O. (2008). Social support and symptom distress in adolescents/young adults with cancer. *Journal of Pediatric Oncology Nursing, 25*(5), 275-284. doi:10.1177/1043454208321117

Crook, B., & Love, B. (2017). Examining the light and dark of an online young adult cancer support community. *Qualitative Evaluation, 27*(6), 938-948. doi:10.1177/1049732316672638

D'Agostino, N. M., & Edelstein, K. (2013). Psychosocial challenges and resource needs of young adult cancer survivors: implications for program development. *Journal of Psychosocial Oncology, 31*(6), 585-600. doi:10.1080/07347332.2013.835018

D'Agostino, N. M., Penney, A., & Zebrack, B. (2011). Providing developmentally appropriate psychosocial care to adolescent and young adult cancer survivors. *Cancer, 117*(10 Suppl), 2329-2334. doi:10.1002/cncr.26043

Decker, C. L. (2007). Social support and adolescent cancer survivors: A review of the literature. *Psycho-Oncology, 16*(1), 1-11. doi:10.1002/pon.1073

DeRouen, M. C., Smith, A. W., Tao, L., Bellizzi, K. M., Lynch, C. F., Parsons, H. M., . . . for the, A. Y. A. H. S. C. G. (2015). Cancer-related information needs and cancer's impact on control over life influence health-related quality of life among adolescents and young adults with cancer. *Psycho-Oncology*. doi:10.1002/pon.3730

Dobinson, K. A., Hoyt, M. A., Seidler, Z. E., Beaumont, A. L., Hullmann, S. E., & Lawsin, C. R. (2016). A grounded theory investigation into the psychosexual unmet needs of adolescent and young adult cancer survivors. *Journal of Adolescent and Young Adult Oncology, 5*(2), 135-145. doi:10.1089/jayao.2015.0022

Drew, S. (2007). 'Having cancer changed my life, and changed my life forever': survival, illness legacy and service provision following cancer in childhood. *Chronic Illness, 3*(4), 278-295. doi:10.1177/1742395307085236

Dukes Holland, K., & Holahan, C. K. (2003). The Relation of Social Support and Coping to Positive Adaptation to Breast Cancer. *Psychology & Health, 18*(1), 15-29. doi:10.1080/0887044031000080656

Dyson, G. J., Thompson, K., Palmer, S., Thomas, D. M., & Schofield, P. (2012). The relationship between unmet needs and distress amongst young people with cancer. *Support Care Cancer, 20*(1), 75-85. doi:10.1007/s00520-010-1059-7

Elkind, D. (1967). Egocentrism in adolescence. *Child Development, 38*(4), 1025-1034. doi:10.2307/1127100

Enskar, K., & von Essen, L. (2007). Prevalence of aspects of distress, coping, support and care among adolescents and young adults undergoing and being off cancer treatment. *European Journal of Oncology Nursing, 11*(5), 400-408. doi:10.1016/j.ejon.2007.01.003

Erikson, E. H. (1970a). Autobiographical notes on the identity crisis. *Daedalus, 99*(4), 730-759.

Erikson, E. H. (1970b). Reflections on the dissent of contemporary youth. *Daedalus, 99*(1), 154-176.

Erikson, E. H., Erikson, J. M., & Kivnick, H. Q. (1986). *Vital involvement in old age: The experience of old age in our time*. New York: W.W. Norton & Company.

Evan, E. E., & Zeltzer, L. K. (2006). Psychosocial dimensions of cancer in adolescents and young adults. *Cancer, 107*(7 Suppl), 1663-1671. doi:10.1002/cncr.22107

Fardell, J. E., Wakefield, C. E., Patterson, P., Lum, A., Cohn, R. J., Pini, S. A., & Sansom-Daly, U. M. (2018). Narrative review of the educational, vocational, and financial needs of adolescents and young adults with cancer: recommendations for support and research. *Journal of Adolescent and Young Adult Oncology, 7*(2), 143-147.

Flanagan, J., & Holmes, S. (2000). Social perceptions of cancer and their impacts: Implications for nursing practice arising from the literature. *Journal of Advanced Nursing, 32*(3), 740-749.

Forsythe, L. P., Alfano, C. M., Kent, E. E., Weaver, K. E., Bellizzi, K., Neeraj, A., . . . Rowland, J. H. (2014). Social support, self-efficacy for decision-making, and follow-up care use in long-term survivors. *Psycho-Oncology, 23*, 788-796. doi:10.1002/pon.3480

Gibbs, J. J. (2002). *The effect of cancer on young adult psychosocial development.* (Doctor of Philosophy). California School of Professional Psychology at Alameda, Ann Arbor, MI.

Goldfarb, M., & Casillas, J. (2014). Unmet information and support needs in newly diagnosed thyroid cancer: comparison of adolescents/young adults (AYA) and older patients. *Journal of Cancer Survivorship, 8*(3), 394-401. doi:10.1007/s11764-014-0345-7

Goldfried, M. R., Padawer, W., & Robins, C. (1984). Social anxiety and the semantic structure of heterosocial interactions *Journal of Abnormal Psychology, 93*(1), 87-97.

Gorman, J. R., Su, H. I., Roberts, S. C., Dominick, S. A., & Malcarne, V. L. (2015). Experiencing reproductive concerns as a female cancer survivor is associated with depression. *Cancer, 121*(6), 935-942. doi:10.1002/cncr.29133

Grealy, L. (1994). *Autobiography of a Face*. New York: HarperCollins.

Gurowka, K. J., & Lightman, E. S. (1995). Supportive and Unsupportive Interactions as Perceived by Cancer Patients. *Social Work in Health Care, 21*(4), 71-88. doi:10.1300/J010v21n04_05

Haase, J. E., & Phillips, C. R. (2004). The Adolescent/Young Adult Experience. *Journal of Pediatric Oncology Nursing, 21*(3), 145-149. doi:10.1177/1043454204264385

Halvorsen, J. F., Sund, A. M., Zeltzer, L., Adnanes, M., Jensberg, H., Eikemo, T. A., . . . Reinfjell, T. (2018). Health-related quality of life and psychological distress in young adult survivors of childhood cancer and their association with treatment, education, and demographic factors. *Qualitative health research, 27*(2), 529-537. doi:10.1007/s11136-017-1716-0

Harloff, J., & Coxon, A. P. (2007). *How to SortA short guide on sorting investigations* (Vol. Version 1.1). Retrieved from http://www.methodofsorting.com/HowToSort1-1_english.pdf

Harvey, S. T., Bimler, D., Evans, I. M., Kirkland, J., & Pechtel, P. (2012). Mapping the classroom emotional environment. *Teaching and Teacher Education, 28*(4), 628-640. doi:10.1016/j.tate.2012.01.005

Hexdall, C. M., & Huebner, E. S. (2008). Subjective Well-Being in Pediatric Oncology Patients. *Applied Research in Quality of Life, 2*(3), 189-208. doi:10.1007/s11482-008-9037-7

Hilton, S., Emslie, C., Hunt, K., Chapple, A., & Ziebland, S. (2009). Disclosing a cancer diagnosis to friends and family: A gendered analysis of young men's and women's experiences *Qualitative health research, 19*(6), 744-754. doi:10.1177/1049732309334737

Howard, A. F., Tan de Bibiana, J., Smillie, K., Goddard, K., Pritchard, S., Olson, R., & Kazanjian, A. (2014). Trajectories of social isolation in adult survivors of childhood cancer. *Journal of Cancer Survivorship, 8*(1), 80-93. doi:10.1007/s11764-013-0321-7

Hydeman, J. A., Uwazurike, O. C., Adeyemi, E. I., & Beaupin, L. K. (2019). Survivorship needs of adolescent and young adult cancer survivors: a concept mapping analysis. *Journal of Cancer Survivorship, 13*(1), 34-42. doi:10.1007/s11764-018-0725-5

Iannarino, N. T., Scott, A. M., & Shaunfield, S. L. (2017). Normative social support in young adult cancer survivors. *Qualitative health research, 27*(2), 271-284. doi:10.1177/1049732315627645

Jankowski, P. J., Clark, W. M., & Ivey, D. C. (2000). Fusing horizons: Exploring qualitative research and psychotherapeutic applications of social constructionism. *Contemporary Family Therapy, 22*(2), 241-250.

Jones, B. L., Parker-Raley, J., & Barczyk, A. (2011). Adolescent cancer survivors: identity paradox and the need to belong. *Qualitative health research, 21*(8), 1033-1040. doi:10.1177/1049732311404029

Kameny, R. R., & Bearison, D. J. (2002). Cancer narratives of adolescents and young adults: A quantitative and qualitative analysis. *Children's Health Care, 31*(2), 143-173.

Kent, E. E., Parry, C., Sender, L. S., Morris, R. A., & Anton-Culver, H. (2012). "You're too young for this": Adolescent and Young Adults' Perspectives on Cancer Survivorship. *Journal of Psychosocial Oncology, 30*, 260-279. doi:10.1080/07347332.2011.644396

Kent, E. E., Smith, A. W., Keegan, T. H., Lynch, C. F., Wu, X. C., Hamilton, A. S., . . . Harlan, L. C. (2013). Talking About Cancer and Meeting Peer Survivors: Social Information Needs of Adolescents and Young Adults Diagnosed with Cancer. *Journal of Adolescent and Young Adult Oncology, 2*(2), 44-52. doi:10.1089/jayao.2012.0029

Kivnick, H. Q., & Wells, C. K. (2014). Untapped richness in Erik H. Erikson's rootstock. *Gerontologist, 54*(1), 40-50. doi:10.1093/geront/gnt123

Kruskal, J. B. (1964). Multidimensional scaling by optimizing goodness of fit to a nonmetric hypothesis. *Psychometrika, 29*(1), 1-27.

Kwak, M., Zebrack, B., Meeske, K. A., Embry, L., Aguilar, C., Block, R., . . . Cole, S. (2013). Prevalence and predictors of post-traumatic stress symptoms in adolescent and young adult cancer survivors: a 1-year follow-up study. *Psycho-Oncology, 22*(8), 1798-1806. doi:10.1002/pon.3217

Lally, R. M., Hydeman, J. A., Schwert, K. T., & Edge, S. B. (2013). Unsupportive social interactions in the weeks immediately following breast cancer diagnosis.

Journal of Psychosocial Oncology, 31(4), 468-488. doi:10.1080/07347332.2013.798758

Landier, W., Hawkins, S., & Leonard, M. (2007). Establishing and enhancing services for childhood cancer survivors: long-term follow-up program resource guide. *Children's Oncology Group*.

Lang, M. J., Giese-Davis, J., Patton, S. B., & Campbell, D. J. T. (2018). Does age matter? Comparing post-treatment psychosocial outcomes in young adult and older adult cancer survivors with their cancer-free peers. *Psycho-Oncology, 27*, 1404-1411. doi:10.1002/pon.4490

Leal, I., Engebretson, J., Cohen, L., Rodriguez, A., Wangyal, T., Lopez, G., & Chaoul, A. (2015). Experiences of paradox: a qualitative analysis of living with cancer using a framework approach. *Psycho-Oncology, 24*(2), 138-146. doi:10.1002/pon.3578

Lehmann, V., Grönqvist, H., Engvall, G., Ander, M., Tuinman, M. A., Hagedoorn, M., . . . von Essen, L. (2014). Negative and positive consequences of adolescent cancer 10 years after diagnosis: an interview-based longitudinal study in Sweden. *Psycho-Oncology, 23*, 1229-1235. doi:10.1002/pon

Lehto, U. S., Ojanen, M., & Kellokumpu-Lehtinen, P. (2005). Predictors of quality of life in newly diagnosed melanoma and breast cancer patients. *Annals of Oncology, 16*(5), 805-816. doi:10.1093/annonc/mdi146

Lehto-Jarnstedt, U. S., Ojanen, M., & Kellokumpu-Lehtinen, P. (2004). Cancer-specific social support received by newly diagnosed cancer patients: validating the new Structural-Functional Social Support Scale (SFSS) measurement tool. *Support Care Cancer, 12*(5), 326-337. doi:10.1007/s00520-004-0620-7

Lewis, P., Jordens, C. F., Mooney-Somers, J., Smith, K., & Kerridge, I. (2013). Growing up with cancer: accommodating the effects of cancer into young people's social lives. *Journal of Pediatric Oncology Nursing, 30*(6), 311-319. doi:10.1177/1043454213513839

Love, B., Crook, B., Thompson, C. M., Zaitchik, S., Knapp, J., Lefebvre, L., . . . Rechis, R. (2012). Exploring psychosocial support online: a content analysis of messages in an adolescent and young adult cancer community. *Cyberpsychology, Behaviour and Social Networking, 15*(10), 555-559. doi:10.1089/cyber.2012.0138

Malicka, I., Kozlowska, A., Wozniewski, M., Rymaszewska, J., & Szczepanska-Gieracha, J. (2016). The role of social support in women's health and recovery processes. *Psychology, Health and Medicine, 21*(1), 81-91. doi:http://dx.doi.org/10.1080/13548506.2015.1009378

Marwick, A. (2016). *Organising therapists' emotional-social skills: are therapists that different?* (Doctor of Clinical Psychology). Massey University, Palmerston North, New Zealand.

Masche, J. G. (2008). Reciprocal influences between developmental transitions and parent-child relationships in young adulthood. *International Journal of Behavioural Development, 32*(5), 401-411. doi:10.1177/0165025408093658

McGoldrick, D., Gordon, P., Whiteson, M., Adams, H., Rogers, P., & Sutcliffe, S. (2011). Awareness and advocacy for adolescents and young adults with cancer. *Cancer, 117*(10 Suppl), 2311-2315. doi:10.1002/cncr.26055

McGrady, M. E., Brown, G. A., & Pai, A. L. H. (2016). Medication adherence decision-making among adolescents and young adults with cancer. *European Journal* *of Oncology Nursing, 20*, 207-214. doi:http://dx.doi.org/10.1016/j.ejon.2015.08.007

McLaughlin, M., Nam, Y., Gould, J., Pade, C., Meeske, K. A., Ruccione, K. S., & Fulk, J. (2012). A videosharing social networking intervention for young adult cancer survivors. *Computers in Human Behavior, 28*(2), 631-641. doi:10.1016/j.chb.2011.11.009

Meyerowitz, B. E., Levin, K., & Harvey, J. H. (1997). On the nature of cancer patients' social interactions. *Journal of Personal and Interpersonal Loss, 2*(1), 49-69. doi:10.1080/10811449708414405

Miles, S. (2000). Topic of cancer. *Good Weekend Melbourne,* 32-34.

Miller, G. A. (1969). A psychological method to investigate verbal concepts. *Journal of Mathematical Psychology, 6*, 169-191. doi:https://doi.org/10.1016/0022-2496(69)90001-7

Ministry of Health. (2017). Retrieved from https://www.health.govt.nz/publication/new-cancer-registrations-2015

Ministry of Health. (2018). Retrieved from https://www.health.govt.nz/publication/cancer-historical-summary-1948-2015

Moolenaar, N. M., Sleegers, P. J. C., Karsten, S., & Daly, A. J. (2012). The social fabric of elementary schools: a network typology of social interaction among teachers. *Educational Studies, 38*(4), 355-371. doi:10.1080/03055698.2011.643101

Mujumdar, U., Lanzarini, V., Lowe, M., Bolinder, B., & Doleh, Y. (2018). A patient-derived conceptual framework of lung cancer care priorities. *Journal of*

Clinical Oncology, 36(30_suppl), 206-206. doi:10.1200/JCO.2018.36.30_suppl.206

Nausheen, B., Gidron, Y., Peveler, R., & Moss-Morris, R. (2009). Social support and cancer progression: a systematic review. *Journal of Psychosomatic Research, 67*(5), 403-415. doi:10.1016/j.jpsychores.2008.12.012

Nielson, J. (2004). Card Sorting: How many users to test. Retrieved from https://www.nngroup.com/articles/card-sorting-how-many-users-to-test/

Olsen, P. R., & Harder, I. (2011). Caring for teenagers and young adults with cancer: a grounded theory study of network-focused nursing. *European Journal of Oncology Nursing, 15*(2), 152-159. doi:10.1016/j.ejon.2010.07.010

Padhye, B., & Gabriel, M. (2013). Cancer in adolescents and young adults In K. S. M. Kohn (Ed.), *Clinical Handbook In Adolescent Medicine, A Guide For Health Professionals Who Work With Adolescents and Young Adults* (pp. 569-577). Singapore: World Scientific Publishing Co.

Paterson, C., Jones, M., Rattray, J., Lauder, W., & Nabi, G. (2016). What is the mechanism effect that links social support to coping and psychological outcome within individuals affected by prostate cancer? Real time data collection using mobile technology. *European Journal of Oncology Nursing, 21*, 126-133. doi:http://dx.doi.org/10.1016/j.ejon.2015.09.002

Patterson, P., McDonald, F. E. J., Zebrack, B., & Medlow, S. (2015). Emerging issues among adolescent and young adult cancer survivors. *Seminars in Oncology Nursing, 31*(1), 53-59. doi:http://dx.doi.org/10.1016/j.soncn.2014.11.006

Pettit, T., & Watson, H. (2016). *Service Provision for Adolescent and Young Adult Cancer Patients in New Zealand including Standards of Care*. Retrieved from New Zealand:

Phillips, F., & Jones, B. L. (2014). Understanding the lived experience of Latino adolescent and young adult survivors of childhood cancer. *Journal of Cancer Survivorship, 8*(1), 39-48. doi:10.1007/s11764-013-0310-x

Pratt-Chapman, M., Willis, A., Bretsch, J., & Patierno, S. R. (2013). Improving cancer survivorship for adolescents and young adults. *Journal of Oncology Navigation and Survivorship, 4*(1), 14-19.

Quinn, G. P., Goncalves, V., Sehovic, I., Bowman, M. L., & Reed, D. R. (2015). Quality of life in adolescent and young adult cancer patients: a systematic review of the literature. *Patient Related Outcome Measures, 6*, 19-51. doi:10.2147/PROM.S51658

Rabin, C. (2019). Self-disclosure to peers by young adult cancer survivors. *Psycho-Oncology, 28*(1), 181-186. doi:10.1002/pon.4930

Rabin, C., Simpson, N., Morrow, K., & Pinto, B. (2013). Intervention format and delivery preferences among young adult cancer survivors. *International Journal of Behavioural Medicine, 20*, 304-310.

Raskin, J. D. (2002). Constructivism in psychology: Personal construct psychology, radical constructivism, and social constructionism. *American communication journal, 5*(3), 1-25.

Richter, D., Koehler, M., Friedrich, M., Hilgendorf, I., Mehnert, A., & Weissflog, G. (2015). Psychosocial interventions for adolescents and young adult cancer patients: A systematic review and meta-analysis. *Criticial Reviews in Oncology/Hematology, 95*(3), 370-386. doi:10.1016/j.critrevonc.2015.04.003

Robinson, L., Miedema, B., & Easley, J. (2014). Young adult cancer survivors and the challenges of intimacy. *Journal of Psychosocial Oncology, 32*(4), 447-462. doi:10.1080/07347332.2014.917138

Rosenblatt, S. E. (2013). *Understanding alliance ruptures: What do they look like?* (Master of Arts). Massey University, Palmerston North.

Shapiro, J. (1990). Patterns of psychosocial performance in the doctor-patient encounter: a study of family practice residents. *Social Science & Medicine, 31*(9), 1035-1041.

Shumaker, S. A., & Brownell, A. (1984). Toward a theory of social support: closing conceptual gaps. *Journal of Social Issues, 40*(4), 11-36. doi:10.1111/j.1540-4560.1984.tb01105.x

Simon, A. E., Wardle, J., & Miles, A. (2011). Is it time to change the stereotype of cancer: the expert view. *Cancer Causes Control, 22*(1), 135-140. doi:10.1007/s10552-010-9683-6

Smith, A. W., Parsons, H. M., Kent, E. E., Bellizzi, K., Zebrack, B., Keel, G., . . . Group, A. H. S. C. (2013). Unmet Support Service Needs and Health-Related Quality of Life among Adolescents and Young Adults with Cancer: The AYA HOPE Study. *Frontiers in Oncology, 3*, 75. doi:10.3389/fonc.2013.00075

Smollar, J., & Youniss, J. (1989). Transformations in Adolescents' Perceptions of Parents. *International Journal of Behavioral Development, 12*(1), 71-84.

Soanes, L., & Gibson, F. (2018). Protecting an adult identity: a grounded theory of supportive care for young adults recently diagnosed with cancer. *International Journal of Nursing Studies, 81*, 40-48. doi:10.1016/j.ijnurstu.2018.01.010

Somekh, B. (1995). The contribution of action research to development in social endeavours: a position paper on action research methodology. *British Educational Research Journal, 21*(3), 339-355.

Song, H., Nam, Y., Gould, J., Sanders, W. S., McLaughlin, M., Fulk, J., . . . Ruccione, K. S. (2012). Cancer survivor identity shared in a social media intervention. *Journal of Pediatric Oncology Nursing, 29*(2), 80-91. doi:10.1177/1043454212438964

Stegenga, K. (2014). Impact of a teen weekend on the social support needs of adolescents with cancer. *Journal of Pediatric Oncology Nursing, 31*(5), 293-297. doi:10.1177/1043454214531858

Stegenga, K., & Macpherson, C. F. (2014). "I'm a survivor, go study that word and you'll see my name": adolescent and cancer identity work over the first year after diagnosis. *Cancer Nursing, 37*(6), 418-428.

Straehla, J. P., Barton, K. S., Yi-Frazier, J. P., Wharton, C., Baker, K. S., Bona, K., . . . Rosenberg, A. R. (2017). The benefits and burdens of cancer: a prospective longitudinal cohort study of adolescents and young adults. *Journal of palliative medicine, 20*(5), 494-501.

Taylor, S. J., Bogdan, R., & DeVault, M. (2015). *Introduction to qualitative research methods: A guidebook and resource*: John Wiley & Sons.

Teall, T., Barrera, M., Barr, R., Silva, M., & Greenberg, M. (2013). Psychological resilience in adolescent and young adult survivors of lower extremity bone tumors. *Pediatric Blood Cancer, 60*(7), 1223-1230. doi:10.1002/pbc.24441

Thompson, K., Palmer, S., & Dyson, G. (2009). Adolescents & young adults: issues in transition from active therapy into follow-up care. *European Journal of Oncology Nursing, 13*(3), 207-212. doi:10.1016/j.ejon.2009.05.001

Tremolada, M., Bonichini, S., Basso, G., & Pillon, M. (2016). Perceived social support and health-related quality of life in AYA cancer survivors and controls. *Psycho-Oncology, 25*, 1408-1417. doi:10.1002/pon.4072

Tsangaris, E., Johnson, J., Taylor, R., Fern, L., Bryant-Lukosius, D., Barr, R., . . . Klassen, A. (2014). Identifying the supportive care needs of adolescent and young adult survivors of cancer: a qualitative analysis and systematic literature review. *Support Care Cancer, 22*, 947-959. doi:10.1007/s00520-013-2053-7

Vaismoradi, M., Jones, J., Turunen, H., & Snelgrove, S. (2016). Theme development in qualitative content analysis and thematic analysis. *Journal of Nursing Education and Practice, 6*(5), 100-110. doi:10.5430/jnep.v6n5p100

Vrontaras, N. (2018). Cancer patients' views on the family changes and the family social support. *Journal of European Psychology Students, 9*(1), 16-27. doi:https://doi.org/10.5334/jeps.403

Wakefield, C. E., McLoone, J., Butow, P., Lenthen, K., & Cohn, R. J. (2013). Support after the completion of cancer treatment: perspectives of Australian adolescents and their families. *European Journal of Cancer Care (Engl), 22*(4), 530-539. doi:10.1111/ecc.12059

Weller, S. C., & Romney, A. K. (1988). Pile sort I: single sorts. In *Systematic Data Collection* (pp. 21-27). Newbury Park: SAGE Publications, Inc.

Wesley, K. M., Zelikovsky, N., & Schwartz, L. A. (2013). Physical symptoms, perceived social support, and affect in adolescents with cancer. *Journal of Psychosocial Oncology, 31*(4), 451-467. doi:10.1080/07347332.2013.798761

Wiener, L., Weaver, M. S., Bell, C. J., & Sansom-Daly, U. M. (2015). Threading the cloak: palliative care education for care providers of adolescents and young adults with cancer. *Clinical Oncology in Adolescents and Young Adults, 5*, 1-18. doi:10.2147/COAYA.S49176

Williams, L. K., McCarthy, M. C., Eyles, D. J., & Drew, S. (2013). Parenting a child with cancer: Perceptions of adolescents and parents of adolescents and younger children following completion of childhood cancer treatment. *Journal of Family Studies, 19*(1), 80-89.

Williamson, H., Harcourt, D., Halliwell, E., Frith, H., & Wallace, M. (2010). Adolescents' and parents' experiences of managing the psychosocial impact of appearance change during cancer treatment. *Journal of Pediatric Oncology Nursing, 27*(3), 168-175. doi:10.1177/1043454209357923

Wills, T. A., & O'Carroll Bantum, E. (2012). Social support, self-regulation, and resilience in two populations: general-population adolescents and adult cancer survivors. *Journal of Social and Clinical Psychology, 31*(6), 568-592.

Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology & Health, 15*, 215-228.

Yoo, G. J., Aviv, C., Levine, E. G., Ewing, C., & Au, A. (2010). Emotion work: disclosing cancer. *Support Care Cancer, 18*(2), 205-215. doi:10.1007/s00520-009-0646-y

Zebrack, B. (2000). Cancer survivor identity and quality of life. *Cancer Practice, 8*(5).

Zebrack, B. (2011). Psychological, social, and behavioral issues for young adults with cancer. *Cancer, 117*(10 Suppl), 2289-2294. doi:10.1002/cncr.26056

Zebrack, B., Bleyer, A., Albritton, K., Medearis, S., & Tang, J. (2006). Assessing the health care needs of adolescent and young adult cancer patients and survivors. *Cancer, 107*(12), 2915-2923. doi:10.1002/cncr.22338

Zebrack, B., Chesler, M. A., & Kaplan, S. (2010). To foster healing among adolescents and young adults with cancer: what helps? What hurts? *Support Care Cancer, 18*(1), 131-135. doi:10.1007/s00520-009-0719-y

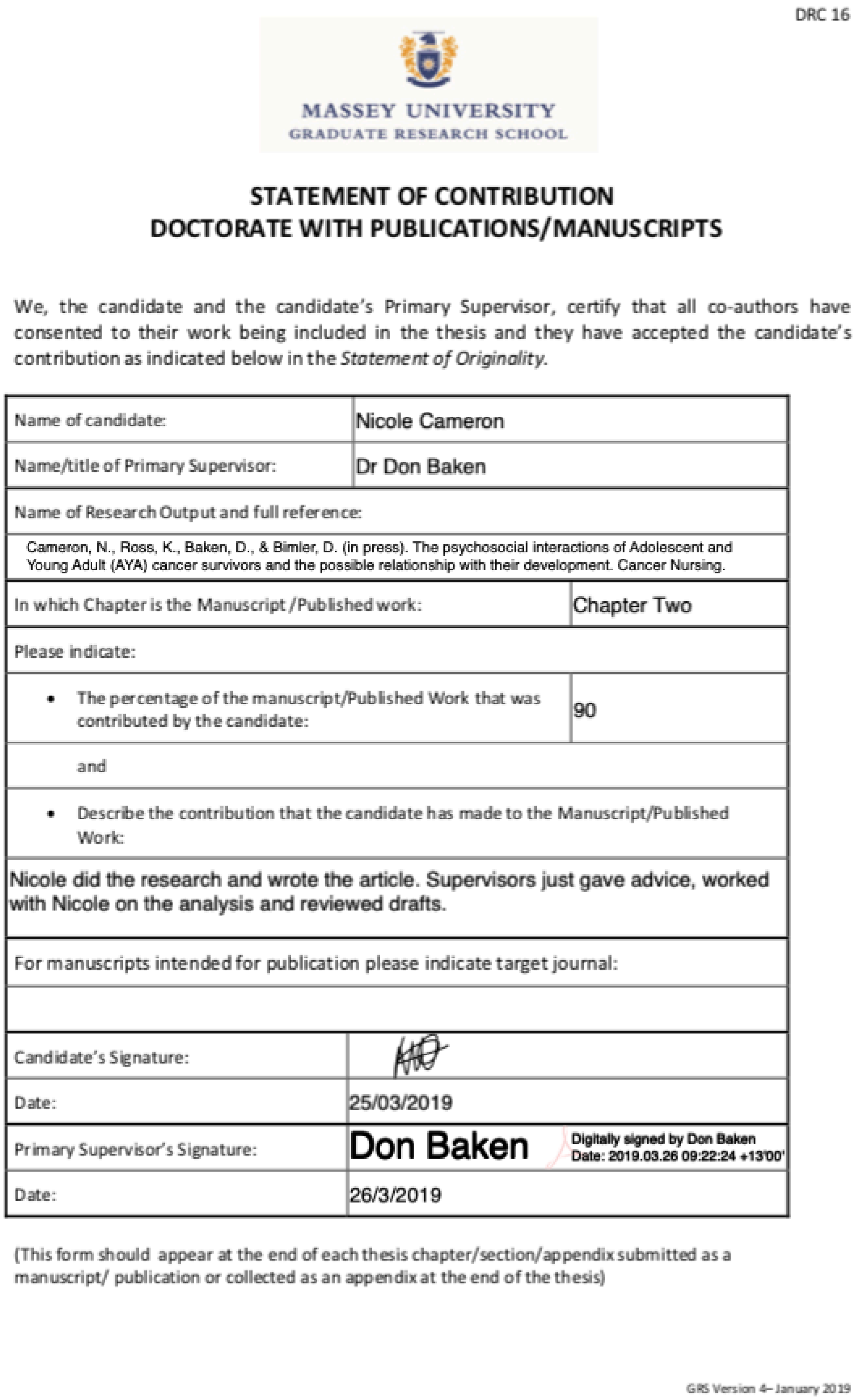
Zebrack, B., & Isaacson, S. (2012). Psychosocial care of adolescent and young adult patients with cancer and survivors. *Journal of Clinical Oncology, 30*(11), 1221-1226. doi:10.1200/JCO.2011.39.5467

Zebrack, B., Kent, E. E., Keegan, T. H., Kato, I., Smith, A. W., & Group, A. H. S. C. (2014). "Cancer sucks," and other ponderings by adolescent and young adult cancer survivors. *Journal of Psychosocial Oncology, 32*(1), 1-15. doi:10.1080/07347332.2013.855959

Zebrack, B., Kwak, M., Salsman, J., Cousino, M., Meeske, K., Aguilar, C., . . . Cole, S. (2015). The relationship between posttraumatic stress and posttraumatic growth among adolescent and young adult (AYA) cancer patients. *Psycho-Oncology, 24*(2), 162-168. doi:10.1002/pon.3585

Appendices

Appendix A: Statements of contribution



DRC 16

MASSEY UNIVERSITY
GRADUATE RESEARCH SCHOOL

STATEMENT OF CONTRIBUTION
DOCTORATE WITH PUBLICATIONS/MANUSCRIPTS

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

Name of candidate:	Nicole Cameron
Name/title of Primary Supervisor:	Dr Don Baken
Name of Research Output and full reference:	
Cameron, N., Ross, K., Baken, D., & Bimler, D. (in press). The psychosocial interactions of Adolescent and Young Adult (AYA) cancer survivors and the possible relationship with their development. Cancer Nursing.	
In which Chapter is the Manuscript /Published work:	Chapter Two
Please indicate:	
• The percentage of the manuscript/Published Work that was contributed by the candidate:	90
and	
• Describe the contribution that the candidate has made to the Manuscript/Published Work:	
Nicole did the research and wrote the article. Supervisors just gave advice, worked with Nicole on the analysis and reviewed drafts.	
For manuscripts intended for publication please indicate target journal:	
Candidate's Signature:	
Date:	25/03/2019
Primary Supervisor's Signature:	Don Baken Digitally signed by Don Baken Date: 2019.03.26 09:22:24 +13'00'
Date:	26/3/2019

(This form should appear at the end of each thesis chapter/section/appendix submitted as a manuscript/ publication or collected as an appendix at the end of the thesis)

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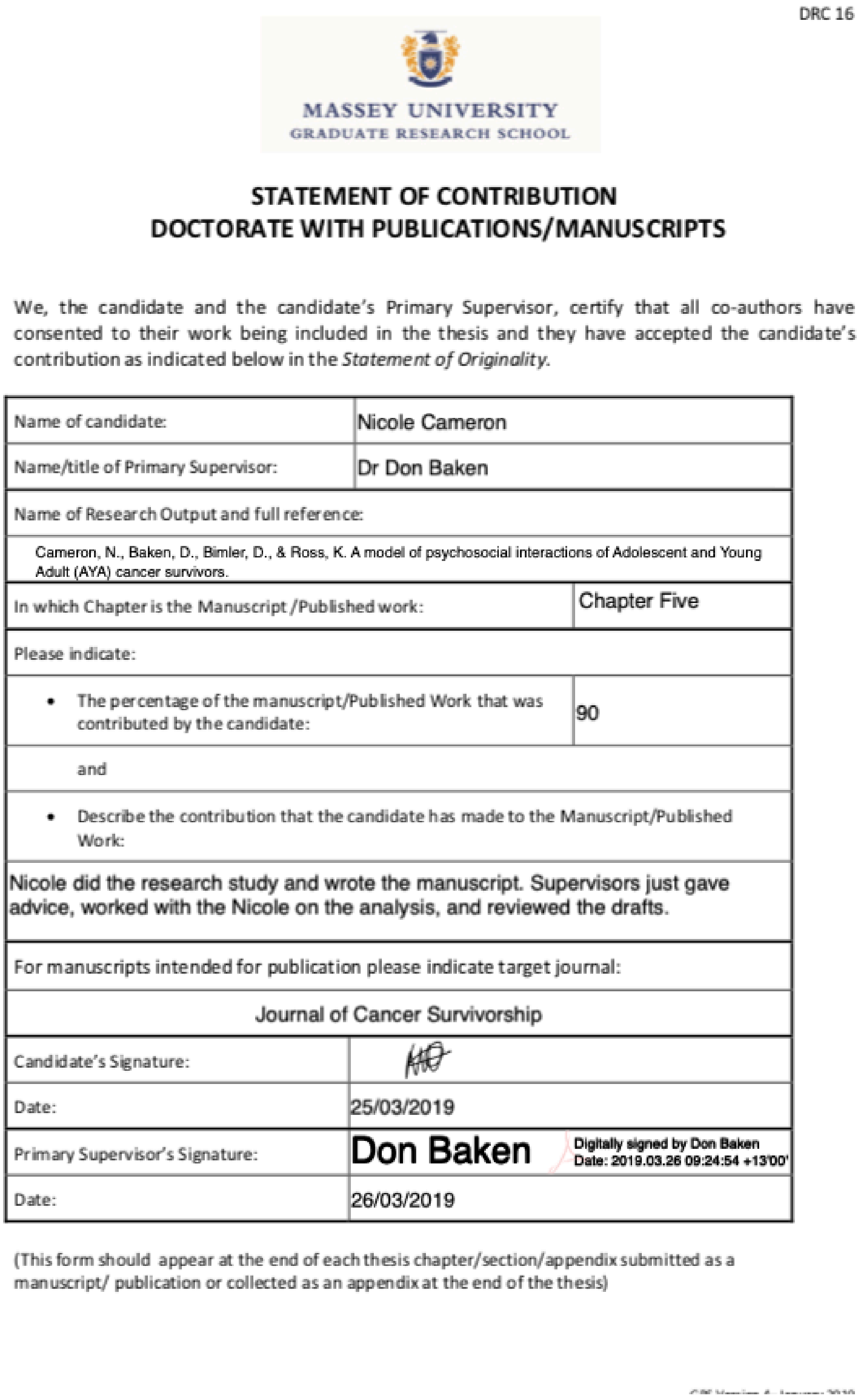

DRC 16

MASSEY UNIVERSITY
GRADUATE RESEARCH SCHOOL

STATEMENT OF CONTRIBUTION
DOCTORATE WITH PUBLICATIONS/MANUSCRIPTS

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

Name of candidate:	Nicole Cameron
Name/title of Primary Supervisor:	Dr Don Baken
Name of Research Output and full reference:	
Cameron, N., Baken, D., Bimler, D., & Ross, K. A model of psychosocial interactions of Adolescent and Young Adult (AYA) cancer survivors.	
In which Chapter is the Manuscript /Published work:	Chapter Five
Please indicate:	
• The percentage of the manuscript/Published Work that was contributed by the candidate:	90
and	
• Describe the contribution that the candidate has made to the Manuscript/Published Work:	
Nicole did the research study and wrote the manuscript. Supervisors just gave advice, worked with the Nicole on the analysis, and reviewed the drafts.	
For manuscripts intended for publication please indicate target journal:	
Journal of Cancer Survivorship	
Candidate's Signature:	
Date:	25/03/2019
Primary Supervisor's Signature:	Don Baken Digitally signed by Don Baken Date: 2019.03.26 09:24:54 +13'00'
Date:	26/03/2019

(This form should appear at the end of each thesis chapter/section/appendix submitted as a manuscript/ publication or collected as an appendix at the end of the thesis)

Appendix B: List of publications and presentations arising from this thesis

Cameron, N. (2015, December). *The psychosocial interactions of Adolescent and Young Adult (AYA) cancer survivors and the possible relationship with their development.* Poster presented at the Inaugural Adolescent and Young Adult Cancer Congress and Summit, Sydney, Australia.

Cameron, N. (2016, September). *The psychosocial interactions of Adolescent and Young Adult (AYA) cancer survivors and the possible relationship with their development.* Poster presented at the New Zealand Psychological Society Conference, Wellington, New Zealand.

Cameron, N. (2016, November). *The psychosocial interactions of Adolescent and Young Adult (AYA) cancer survivors and the possible relationship with their development.* Paper presented at the Psycho-Oncology New Zealand (PONZ) Conference, Wellington, New Zealand.

Cameron, N. (2017, June). *The psychosocial interactions of Adolescent and Young Adult (AYA) cancer survivors and the possible relationship with their development.* Paper presented at the MidCentral DHB radiation therapy study day, Palmerston North, New Zealand.

Cameron, N. (2019, February). *The psychosocial interactions of Adolescent and Young Adult (AYA) cancer survivors and the possible relationship with their development.* Paper presented to the Massey University Psychology Clinic, Palmerston North, New Zealand.

Cameron, N. & Ross, K. (2018, December). *The psychosocial interactions of Adolescent and Young Adult (AYA) cancer survivors and the possible relationship with their development.* Paper presented at the Third Global Adolescent and Young Adult Cancer Congress, Sydney, Australia.

Cameron, N., Ross, K., Baken, D., & Bimler, D. (In Press). The psychosocial interactions of Adolescent and Young Adult (AYA) cancer survivors and the possible relationship with their development. Cancer Nursing.

Cameron, N., Baken, D., Bimler, D., & Ross, K. (2019). A model of psychosocial interactions of Adolescent and Young Adult (AYA) cancer survivors. Unpublished manuscript.

Appendix C: Participant information and consent forms (initial interviews)

MASSEY UNIVERSITY
COLLEGE OF HUMANITIES
AND SOCIAL SCIENCES
TE KURA PŪKENGA TANGATA

The psychosocial interactions of adolescent and young adult cancer survivors and the possible impact on their development

Hi there,
You are invited to take part in a study on young people and cancer. Whether or not you take part is your choice. If you don't want to take part, you don't have to give a reason, and it wont affect the care you receive. If you do want to take part now, but you change your mind later, you can pull out of the study at any time.

This Participant Information Sheet will help you decide if you'd like to take part. It sets out why we are doing the study, what your participation will involve, what the benefits and risks to you might be, and what will happen after the study ends. We will go through this information with you and answer any questions you might have. You do not have to decide today whether or not you will participate in this study. Before you decide you may want to talk about the study with other people, such as family, whānau, friends, or healthcare providers, and we encourage that you do this.

If you agree to take part in this study, you will be asked to sign the Consent Form on the last page of this document. You will be given a copy of both the Participant Information Sheet and the Consent Form to keep. This document is 6 pages long, including the Consent Form. Please make sure you have read and understood all the pages.

Researcher's information:

Hello, I'm Nicole Cameron and I am a postgraduate student at Massey University currently working towards my Doctorate in Clinical Psychology. My research supervisors are Dr. Don Baken (registered clinical psychologist and research coordinator), Dr. Kirsty Ross (senior clinical psychologist and senior lecturer), and Dr. David Bimler (statistical expert), all of whom work at Massey University.

Background information:

This research is part of my work towards a doctoral degree. I have chosen to study the interactions of young people with cancer with others, due to my own experience with cancer as a teenager. It is recognised that social support is an essential part of an individual's experience with cancer but social interactions can be considered both helpful and unhelpful. The latter may prove potentially unhelpful to an individual's physical and psychological health. Adolescents and young adults (AYA) with cancer can be particularly affected by the social interactions related to cancer, as they can be dealing with both a serious illness and normal developmental challenges. The overall study aims to form a comprehensive and complete model of all interactions relevant to AYA patients and cancer. Then, the model will be applied by establishing which interactions occur with family, friends, health professionals and acquaintances or strangers. A further look at these interactions aims to identify the experiences of this population and which interactions are helpful when it comes to interactions with others. As psychosocial development is an important aspect of this age group (16-25 year olds), it is appropriate to consider the impact these interactions may have on the development of AYA patients. It is believed that a better understanding of AYA patients' psychosocial experiences will enable family, friends and health professionals to provide more positive support for young people with cancer.

What is involved?

The overall study is divided into three smaller studies, and this is the first of the smaller studies. In this study I am interested in interviewing adolescents and young adults to ask what helpful or unhelpful interactions have occurred for them throughout their experience with cancer. Questions about interactions involving the participants' own experiences, the meaning of their cancer and how these interactions might have impacted the normal growing-up process will also be included.

I am looking for 10 participants - between ages **16 and 25** - to talk to. Participants **need to have completed treatment**, ideally around 6 months to 3 years ago.

As a reimbursement for your time and to thank you for participating, a $20 supermarket voucher will be provided for all participants.

Please note, for your own safety if you are currently experiencing a mental illness, or have significant ongoing cognitive effects as a result of treatment, you will not be eligible to participate in this study. If you have any questions about this please contact myself, Dr. Baken or Dr. Ross.

What if I say yes?

If you choose to participate, please read this form and let me know if you have any questions. We will then arrange an interview date and time to suit you. I will also arrange where best to meet you – I can come to your house or we can meet at another suitable location, such as at your local CanTeen office. We may also be able to conduct the interview through Skype if that is more convenient. The interview will take up to 90 minutes. You are welcome to bring along a friend or family member for support. I will bring a printed copy of this form with me on the day of the interview for you to sign.

Benefits and risks:

There are a few possible benefits and risks involved if you choose to participate in this study. Benefits may include some relief from sharing your experiences, which could help others. Your participation will help tremendously, not only towards my learning and research, but also hopefully for the benefit of others.

Risks may include feeling upset or distressed while you are talking about your experience with cancer. It is our responsibility to ensure that you are cared for should you become upset, and if this is the case we can refer you to your GP or the Massey University counselling or psychology services.

About your information:

After the interview, I will transcribe the voice recording of our discussion and send it to you to make any changes and comments. Once you are happy with the transcript, I will use the approved version to analyse. All information gathered (e.g. consent forms, recordings and any notes taken during interviews) will be kept confidential. Only you, my supervisors and I will have access to these and they will be stored in a locked cabinet in Dr. Don Baken's office and retained for review purposes. After ten years, this information will be destroyed. The response forms will be kept separate from consent forms. When I write up the thesis, your identity will be kept anonymous and no identifying information (such as your location) will be included to ensure your privacy. Your decision to participate in this research will be kept confidential.

When the study is complete, you can choose to receive a summary of the research findings (you can indicate this on the consent form). I will be available to discuss these results with you if you wish.

Your rights:

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

- Withdraw from the study at any time prior to the transcript being approved, with no explanation required and no disadvantage
- Ask any questions about the study at any time during participation
- Be given access to a summary of the project findings when it is concluded

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Who to contact:

If you would like to know more, please do not hesitate to contact me directly, or you can reach my supervisors with any queries or concerns:

- Nicole Cameron – nicolecameronresearch@hotmail.com or [redacted]
- Dr. Don Baken - D.M.Baken@Massey.ac.nz or 06 356 9099, x 81886
- Dr. Kirsty Ross - K.J.Ross@Massey.ac.nz or 06 356 9099, x 84968

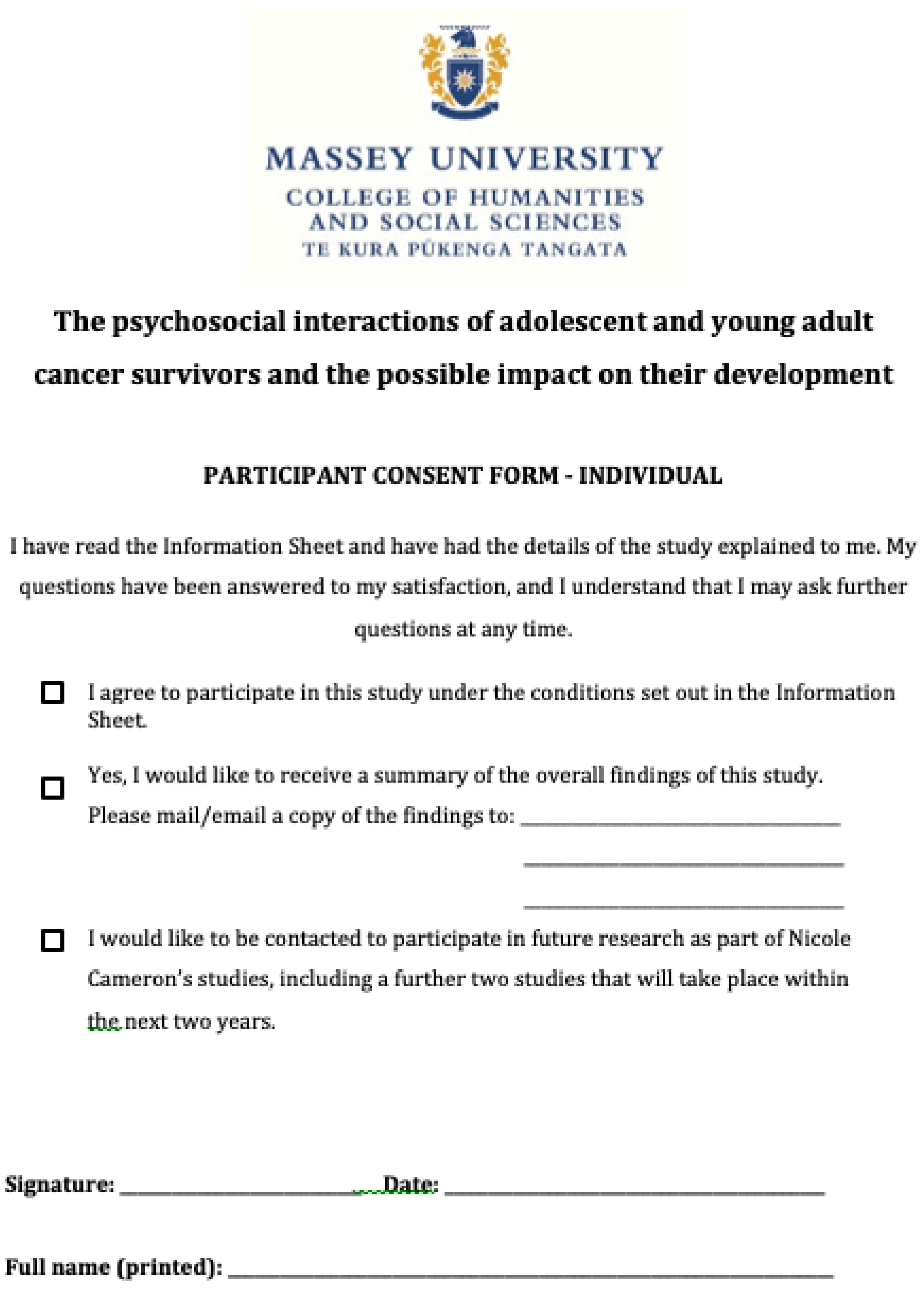
If you want to talk to someone who isn't involved with the study, you can contact an independent health and disability advocate on:

Phone:	0800 555 050
Fax:	0800 2 SUPPORT (0800 2787 7678)
Email:	advocacy@hdc.org.nz

You can also contact the health and disability ethics committee (HDEC) that approved this study on:

Phone:	0800 4 ETHICS
Email:	hdecs@moh.govt.nz

This study has been reviewed and approved by the Central Health and Disability Ethics Committee on 3rd August 2015 based on the full review pathway – application 15/CEN/76. If you have any questions about the conduct of this research please contact the Health and Disability Ethics Committee on 0800 4 ETHICS or email – hdecs@moh.govt.nz



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The psychosocial interactions of adolescent and young adult cancer survivors and the possible impact on their development

PARTICIPANT CONSENT FORM - INDIVIDUAL

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

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

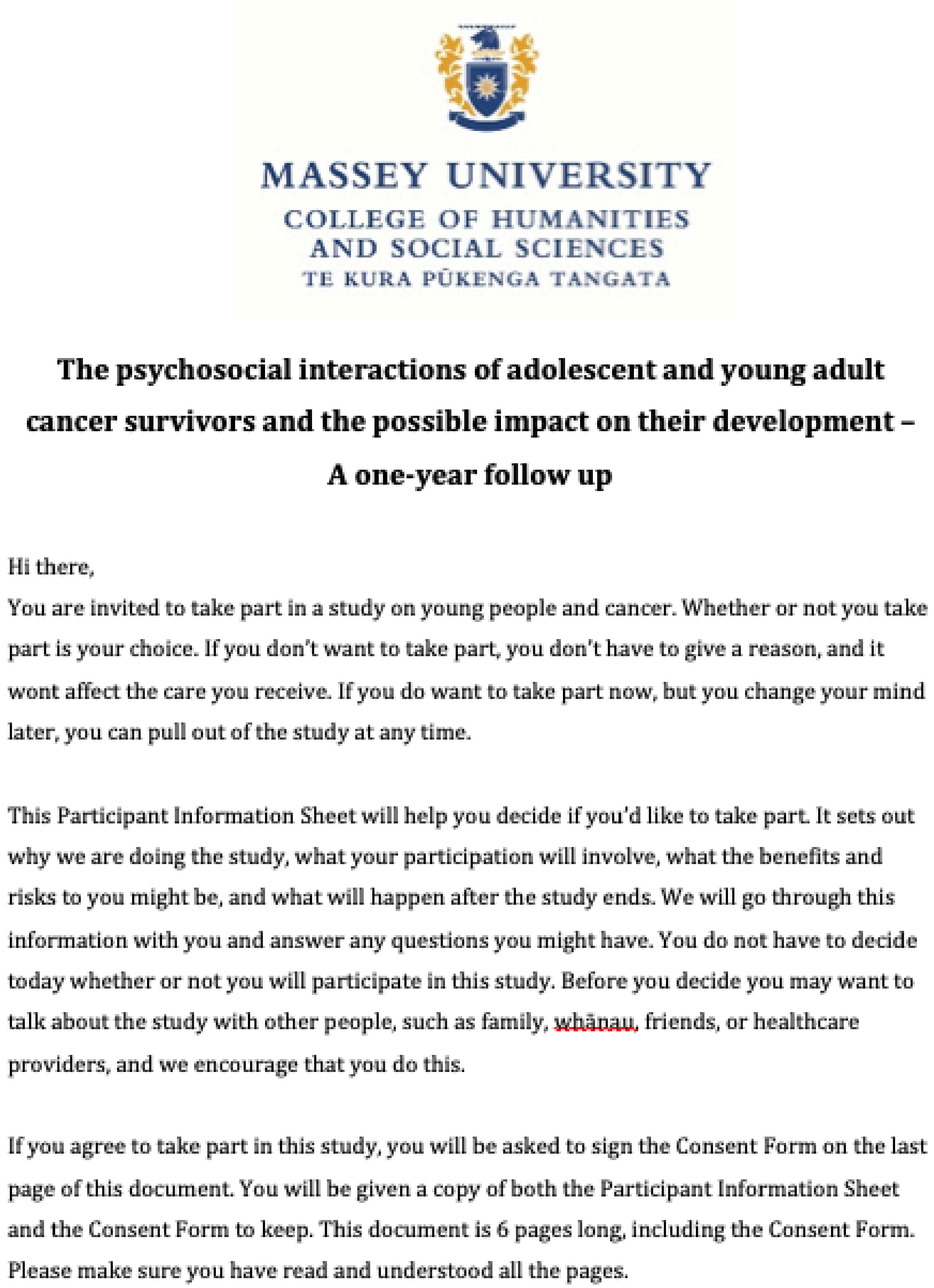
☐ Yes, I would like to receive a summary of the overall findings of this study.
Please mail/email a copy of the findings to: ________________________________
____
____

☐ I would like to be contacted to participate in future research as part of Nicole Cameron's studies, including a further two studies that will take place within the next two years.

Signature: ________________________ **Date:** ________________________________

Full name (printed): ____

Appendix D: Participant information and consent forms (follow-up interviews)



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TE KURA PŪKENGA TANGATA

The psychosocial interactions of adolescent and young adult cancer survivors and the possible impact on their development – A one-year follow up

Hi there,
You are invited to take part in a study on young people and cancer. Whether or not you take part is your choice. If you don't want to take part, you don't have to give a reason, and it wont affect the care you receive. If you do want to take part now, but you change your mind later, you can pull out of the study at any time.

This Participant Information Sheet will help you decide if you'd like to take part. It sets out why we are doing the study, what your participation will involve, what the benefits and risks to you might be, and what will happen after the study ends. We will go through this information with you and answer any questions you might have. You do not have to decide today whether or not you will participate in this study. Before you decide you may want to talk about the study with other people, such as family, whānau, friends, or healthcare providers, and we encourage that you do this.

If you agree to take part in this study, you will be asked to sign the Consent Form on the last page of this document. You will be given a copy of both the Participant Information Sheet and the Consent Form to keep. This document is 6 pages long, including the Consent Form. Please make sure you have read and understood all the pages.

Researcher's information:

Hello, I'm Nicole Cameron and I am a postgraduate student at Massey University currently working towards my Doctorate in Clinical Psychology. My research supervisors are Dr. Don Baken (registered clinical psychologist and research coordinator), Dr. Kirsty Ross (senior clinical psychologist and senior lecturer), and Dr. David Bimler (statistical expert), all of whom work at Massey University.

Background information:

This research is part of my work towards a doctoral degree. I have chosen to study the interactions of young people with cancer with others, due to my own experience with cancer as a teenager. It is recognised that social support is an essential part of an individual's experience with cancer but social interactions can be considered both helpful and unhelpful. The latter may prove potentially unhelpful to an individual's physical and psychological health. Adolescents and young adults (AYA) with cancer can be particularly affected by the social interactions related to cancer, as they can be dealing with both a serious illness and normal developmental challenges. The overall study aims to form a comprehensive and complete model of all interactions relevant to AYA patients and cancer. Then, the model will be applied by establishing which interactions occur with family, friends, health professionals and acquaintances or strangers. One year follow up interviews with participants will aim to explore whether there have been any changes to participants' interactions related to cancer, or the impact of cancer on their development. As psychosocial development is an important aspect of this age group (16-25 year olds), it is appropriate to consider the impact these interactions may have on the development of AYA patients. It is believed that a better understanding of AYA patients' psychosocial experiences will enable family, friends and health professionals to provide more positive support for young people with cancer.

What is involved?

The research project is divided into three smaller studies, and this is the third of the smaller pieces of research. I am interested in re-interviewing the adolescents and young adults who were involved in the first study to see if there have been any changes in their interactions or experiences with others as a result of having cancer. Questions will include asking about interactions involving the participants' own experiences and if or how these experiences and perspectives might have changed over the past year. I will send you a copy of the interview questions before we meet or talk to give you time to think about your answers if you wish.

As a reimbursement for your time and to thank you for participating, a $20 supermarket voucher will be provided for all participants.

Please note, for your own safety if you are currently experiencing a mental illness you may not be eligible to participate in this study. If you have any questions about this please contact myself, Dr. Baken or Dr. Ross.

What if I say yes?

If you choose to participate, please read this form and let me know if you have any questions. We will then arrange an interview date and time to suit you. I will also arrange where best to meet you – I can come to your house or we can meet at another suitable location, such as at your local CanTeen office. We may also be able to conduct the interview through Skype if that is more convenient. The interview may take up to 60 minutes, although it is likely to be shorter than this. You are welcome to bring along a friend or family member for support. I will bring a printed copy of this form with me on the day of the interview for you to sign, or I will post you a copy if we are talking over Skype.

Benefits and risks:

There are a few possible benefits and risks involved if you choose to participate in this study. Benefits may include some relief from sharing your experiences, which could help others. Your participation will help tremendously, not only towards my learning and research, but also hopefully for the benefit of others.

Risks may include feeling upset or distressed while you are talking about your experience with cancer. It is our responsibility to ensure that you are cared for should you become upset, and if this is the case we can refer you to your GP or the Massey University counselling or psychology services.

About your information:

After the interview, I will transcribe the voice recording of our discussion and send it to you to make any changes and comments. Once you are happy with the transcript, I will use the approved version to analyse. All information gathered (e.g. consent forms, recordings and any notes taken during interviews) will be kept confidential. Only you, my supervisors and I will have access to these and they will be stored in a locked cabinet in Dr. Don Baken's office and retained for review purposes. After ten years, this information will be destroyed. The response forms will be kept separate from consent forms. When I write up the thesis, your identity will be kept anonymous and no identifying information (such as your location) will be included to ensure your privacy. Your decision to participate in this research will be kept confidential.

When the study is complete, you can choose to receive a summary of the research findings (you can indicate this on the consent form). I will be available to discuss these results with you if you wish.

Your rights:

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

- Withdraw from the study at any time prior to the transcript being approved, with no explanation required and no disadvantage
- Ask any questions about the study at any time during participation
- Be given access to a summary of the project findings when it is concluded

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Who to contact:

If you would like to know more, please do not hesitate to contact me directly, or you can reach my supervisors with any queries or concerns:

- Nicole Cameron – nicolecameronresearch@hotmail.com or [redacted]
- Dr. Don Baken - D.M.Baken@Massey.ac.nz or 06 356 9099, x 81886
- Dr. Kirsty Ross - K.J.Ross@Massey.ac.nz or 06 356 9099, x 84968

If you want to talk to someone who isn't involved with the study, you can contact an independent health and disability advocate on:

Phone:	0800 555 050
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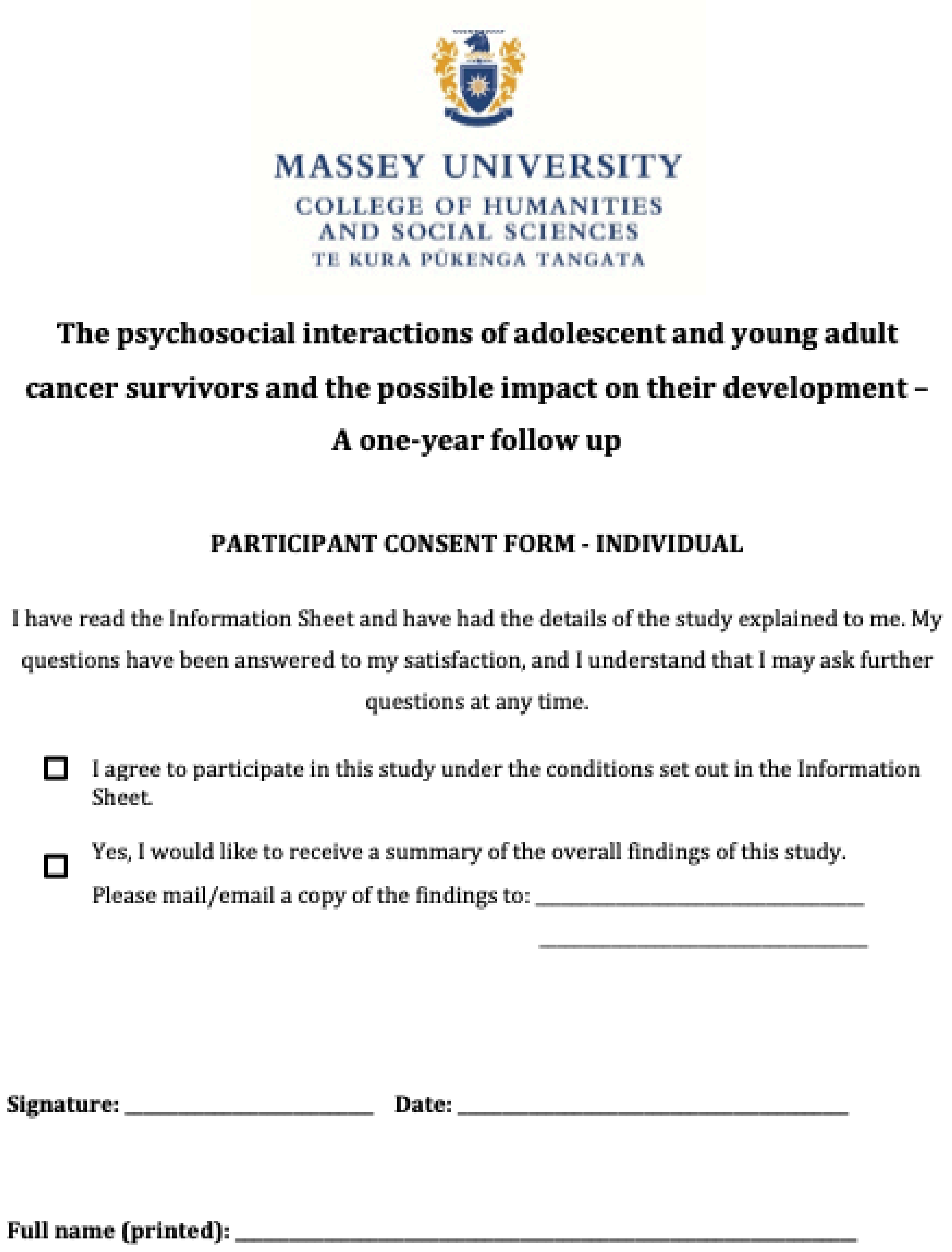
Email:	advocacy@hdc.org.nz

You can also contact the health and disability ethics committee (HDEC) that approved this study on:

Phone:	0800 4 ETHICS
Email:	hdecs@moh.govt.nz

This study has been reviewed and approved by the Central Health and Disability Ethics Committee on 3rd August 2015 based on the full review pathway – application 15/CEN/76. If you have any questions about the conduct of this research please contact the Health and Disability Ethics Committee on 0800 4 ETHICS or email – hdecs@moh.govt.nz



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The psychosocial interactions of adolescent and young adult cancer survivors and the possible impact on their development – A one-year follow up

PARTICIPANT CONSENT FORM - INDIVIDUAL

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

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

☐ Yes, I would like to receive a summary of the overall findings of this study.

Please mail/email a copy of the findings to: ______________________________
____

Signature: ______________________ **Date:** ______________________________

Full name (printed): ____

Appendix E: Interview questions (first interviews 2015)

The psychosocial interactions of adolescent and young adult cancer survivors and the possible impact on their development

Interview questions – Study One

Thank you for participating in this study.

Before we get started, please know that you can choose not to answer any question without explanation. We can stop at any point and we can take a break at any time too.
Are you happy if we get started now?

Opening question:
Tell me about yourself, and your journey so far.

Initial information points to cover (ask if not covered by opening question):

- How old are you?
- Where do you currently live (town or city)?
- What is your ethnicity?
- Are you a member of CanTeen? When did you join?
- What type and stage of cancer did you have, if applicable?
- When did you complete treatment?
- Are you currently in remission?

Interactions:

- Can you tell me about how people have responded to you having cancer? (Ask for examples if needed). Was there a difference in how they responded from when you were diagnosed to now?
- Was there anything in particular that you found helpful? (Ask for examples if needed). How were they helpful?
- Was there anything in particular that you found unhelpful? (Ask for examples if needed). How were they unhelpful?
- Was there anything that people brought up a lot? For example, did you receive lots of questions about how you're feeling, or your type of treatment?
- Has anyone said anything that came across as odd or unusual to you?
- Is there anything you would like to change about how people respond to cancer – especially cancer in young people?
- If you were to speak to another young person who had recently been diagnosed with cancer, what would you say to them?

Themes to ask around (if not already raised by the participant):

- Empowering/disempowering
- Meaning of cancer
- Interactions related to own experience
- Helpful information

Developmental questions:

- What does it mean to you to have cancer as a young person?
- What differences do you think there are between having cancer as a young person and having cancer as an adult?
- How do you think cancer has affected your life, given your age? For example, how has it affected your relationships with family and friends, your education, and any other aspects?
- Has experiencing cancer prevented you from doing anything your friends are doing?
- Has cancer affected your sense of who you are, or how you view yourself?

Do you have any questions for me about the study?

Thank you for participating in this study.

Appendix F: Interview questions (follow up interviews 2016)

The psychosocial interactions of adolescent and young adult cancer survivors and the possible impact on their development – A one year follow up

Thank you for participating in this follow up interview.

Before we get started, please know that you can choose not to answer any question without explanation. We can stop at any point and we can take a break at any time too. Are you happy if we get started now?

The idea of this interview is to catch up one year on from our last interview. Generally, I'd like to hear if anything has changed for you and how this might have affected your experience with cancer. Like last time, I have some questions related to your interactions with others, how others have responded to you having cancer, and how cancer might have affected you as a young person. How does this sound to you?

General:

- How are you?
- How have the last 12 months been for you since we last met?

Interactions:

- Can you tell me about how others' have responded to you having cancer?
- Can you remember any particular discussions or interactions about cancer that have stood out for you? What makes these interactions particularly memorable?
- Have you disclosed your experience of cancer to anyone in the last year? (If so) how did the other person respond?
- Have you found anything particularly helpful about how others respond or behave toward your experience with cancer? How were they helpful?
- How about anything particularly unhelpful?
- Last year you also mentioned that you had experienced (difficulty at school/work/with peers etc). How do you feel about that now?
- Last year you mentioned that (interactions, behaviours or experiences based on notes from previous transcript) was important to you. How do you see that now? Do you feel the same or has this changed?

Developmental questions:

- How do you think cancer has affected your life, given your age?

- Do you think that cancer affected your sense of who you are, or how you view yourself?
- How do you currently reflect on your experience with cancer? What do you think about when you recall this experience?

CanTeen:

- Have there been any changes to your relationship with CanTeen in the last 12 months? (i.e. have you left CanTeen, aged out, reduced or increased involvement)
- How have these changes affected you? Have you experienced any differences in your social life, mood, or in any other area?

Last question:

- What personal strengths do you believe you have gained or developed as a result of experiencing cancer?

Do you have any questions for me about the study? If you think of any questions later on, feel free to email or call/text me (email address and phone number on information sheet).

Thank you for participating in this follow up study.

Appendix G: Item list (quantitative study)

1. Asked about the details of treatment
2. Shared their own experience with cancer
3. Commented that I look good
4. Did more things for me (Opening doors, making cups of tea etc.)
5. Asked if I needed anything
6. Asked me about cancer
7. Asked, “How are you?”
8. Sent messages of support
9. Visited me
10. Avoided talking about cancer
11. Physically avoided me
12. Asked how appointments went
13. Encouraged me to keep going
14. Didn’t treat me any differently
15. Didn’t visit me in hospital
16. Whispered about me
17. Looked at me differently
18. Expressed the idea that cancer could be contagious
19. Asked me if cancer is going to come back
20. Asked me if I’m okay
21. Asked, “Why didn’t you tell me?”
22. Asked me if I’m going to lose my hair
23. Told me cancer is going to change me
24. Tried to give me advice
25. Told me about people they know who have/have had cancer
26. Expressed anger
27. Cried
28. Expressed sympathy towards me

29. Told me “You’ll be fine”
30. Expressed religious belief in my survival
31. Reacted with little emotion
32. Reacted with much surprise
33. Asked me, “Are you okay?”
34. Friends no longer contacted me
35. Talked to me about general topics (excluding cancer)
36. Hide their emotion from me
37. Brought things to entertain me in hospital (books, magazines etc.)
38. Brought me food
39. People turned up unannounced to see me
40. People visit me because they feel they should (not because they want to)
41. Looked sad towards me
42. Said I was trying to get sympathy/attention from having cancer
43. Are over-protective of me
44. Ignored the fact that I had cancer altogether
45. Looked at me, and when I turn around they looked away
46. Brought up fertility preservation
47. Shared information about me with other people without asking me first
48. Teachers said they would make allowances for my illness when marking
49. Tried to be nice by not telling me the truth
50. Brought me gifts
51. Referred to my future
52. Told me how well I was dealing with having cancer
53. Forgot I had cancer
54. Made friendly jokes about the cancer
55. Acted awkwardly around me/Didn’t know what to say
56. Gave me a hug
57. Asked me if cancer is in my family
58. Asked me how I felt about cancer
59. Questioned my behaviour

60. Stared at me
61. Told me they are too busy to hang out with me
62. Assumed that now treatment is over I am fine
63. Consoled me when I am angry
64. Listened to me
65. Told me I will be okay
66. Respected when I wanted to be alone
67. Talked about me without including me in the conversation
68. Ignored my needs
69. Assumed I was happy
70. Either assumed I missed or didn’t miss school
71. Tried to change my emotions towards cancer
72. Assumed my tiredness is attributed to laziness
73. Told me I should be grateful
74. Said “If there’s anything I can do just let me know”
75. Talked on my behalf without letting me answer
76. Made inappropriate jokes
77. Asked very personal questions
78. Blamed my cancer for other people’s problems
79. Commented that I have a good perspective on cancer

Appendix H: Honours item list

PC = Person with cancer

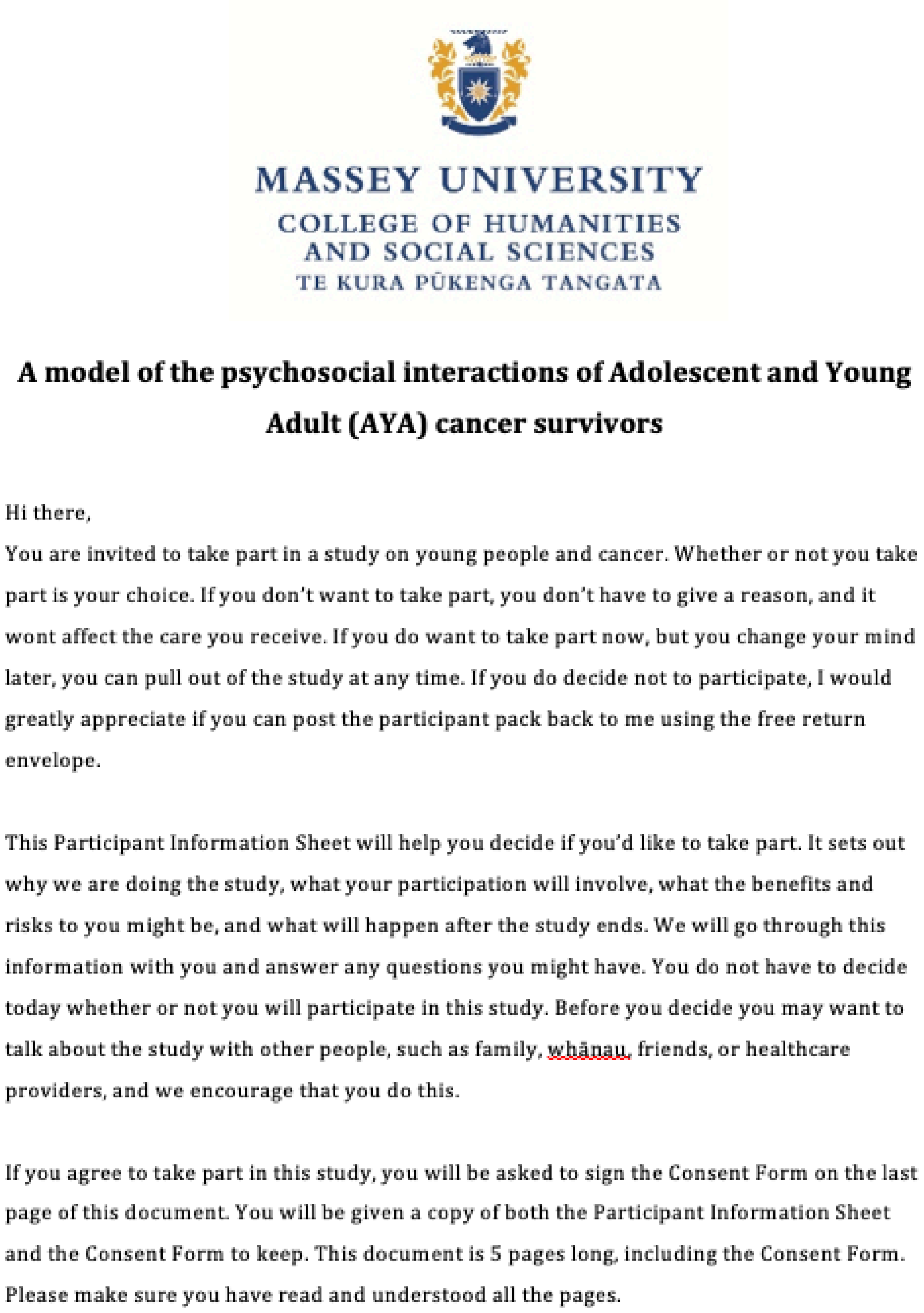
Interaction item descriptors:

1. Says they fear cancer
2. Says cancer is life-threatening/incurable
3. Asks about the details of treatment
4. Tells a story of someone they know who has/had cancer
5. Tells PC he or she knows someone who had a similar/the same disease
6. Tells PC that cancer is a powerful life lesson
7. Tells PC that they are brave
8. Comments on PC's prior healthy lifestyle
9. Comments that PC previously smoked
10. Avoids touching PC
11. Appears anxious to get away
12. Comments on physical changes in PC's body
13. Asks about hair loss/wigs
14. Comments on a positive aspect of cancer (e.g., time spent with family)
15. Suggests alternative medicine/therapy
16. Offers travel assistance to PC
17. Offers to cook meals for PC
18. Sends get-well/well wishes messages
19. Doesn't make eye contact
20. Shares their own experience with cancer
21. Stands far away during interaction
22. Stares at PC throughout interaction
23. Suggests seeing a different doctor
24. Asks how PC is feeling
25. Asks PC how they are coping with cancer
26. Appears optimistic about PC's prognosis

27. Tells PC not to worry, they will be fine
28. Tells PC to cheer up
29. Wells up with tears when talking to PC
30. Stutters during interaction with PC
31. Fidgets during interaction
32. Tells PC he/she shared their story with friends
33. Asks what stage cancer PC has/had
34. Tells PC they know someone who recently died from cancer
35. Informs PC that cancer can rapidly spread
36. Tells PC they are thinking about them or praying for them
37. Suggests taking pen and paper to doctors visits because “you’ll forget details”
38. Tells PC that there is always someone else who is worse off
39. Attitude shifted once the condition was explained
40. Tells PC that they admire PC very much for what they have been through
41. Asks what has happened to PC
42. Phones PC regularly to check up on them
43. Offers to visit PC at home
44. Acknowledges that PC must find some things more difficult since being unwell
45. Appears calm when PC tells them about their health
46. Suggests PC’s situation may have been better if they had seen a doctor sooner
47. Says they would love to talk but they need to be somewhere else
48. Says to PC “call me if you need anything”
49. Changes the subject when PC is talking about cancer
50. Compliments PC on how good they look
51. Dwell’s on PC’s health throughout the interaction
52. Warns PC that some cancer patients suffer from ‘chemo brain’ (mild cognitive impairment following chemotherapy, characterized by memory lapses and poor concentration)
53. Sees PC and asks if they are well enough to be out
54. Extremely cheerful and upbeat towards PC

55. Asks PC why they chose to have a particular treatment (e.g. chemo instead of something else)
56. Asks how cancer has affected PC's family
57. Asks PC whether their type of cancer is contagious
58. States they are impressed that PC is still able to be active
59. Asks PC if their work has been affected by their illness
60. Asks how PC knew something was wrong
61. Tells PC they are "strong enough to beat cancer"
62. Tells PC it won't be long before they feel "back to normal"
63. Asks PC if it is true that a tumor becomes more dangerous if it is exposed to air
64. Expresses anger towards PC's illness on behalf of the PC
65. Makes small talk, but does not ask PC anything about them or their illness
66. Sees PC, briefly smiles but does not talk to PC
67. Offers to put PC in touch with another PC with the same/similar cancer
68. Says to PC "everything happens for a reason"
69. Offers to help find meaning for PC's illness
70. A, former cancer patient encourages PC to fight cancer
71. Asks PC if their experience with cancer has altered their perception of life
72. Asks why PC lost their hair
73. Suggests that PC's illness may be attributable to excessive worry or stress
74. Comments to PC that cancer is now so common that it is almost normal

Appendix I: Participant consent forms



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AND SOCIAL SCIENCES
TE KURA PŪKENGA TANGATA

A model of the psychosocial interactions of Adolescent and Young Adult (AYA) cancer survivors

Hi there,

You are invited to take part in a study on young people and cancer. Whether or not you take part is your choice. If you don't want to take part, you don't have to give a reason, and it wont affect the care you receive. If you do want to take part now, but you change your mind later, you can pull out of the study at any time. If you do decide not to participate, I would greatly appreciate if you can post the participant pack back to me using the free return envelope.

This Participant Information Sheet will help you decide if you'd like to take part. It sets out why we are doing the study, what your participation will involve, what the benefits and risks to you might be, and what will happen after the study ends. We will go through this information with you and answer any questions you might have. You do not have to decide today whether or not you will participate in this study. Before you decide you may want to talk about the study with other people, such as family, whānau, friends, or healthcare providers, and we encourage that you do this.

If you agree to take part in this study, you will be asked to sign the Consent Form on the last page of this document. You will be given a copy of both the Participant Information Sheet and the Consent Form to keep. This document is 5 pages long, including the Consent Form. Please make sure you have read and understood all the pages.

Researcher's information:

Hello, I'm Nicole Cameron and I am a postgraduate student at Massey University currently working towards my Doctorate in Clinical Psychology. My research supervisors are Dr. Don Baken (senior clinical psychologist and research coordinator), Dr. Kirsty Ross (senior clinical psychologist and senior lecturer), and Dr. David Bimler (statistical expert), all of whom work at Massey University.

Background information:

This research is part of my work towards a doctoral degree. I have chosen to study the interactions of young people with cancer with others, due to my own experience with cancer as a teenager. It is recognised that social support is an essential part of an individual's experience with cancer but social interactions can be considered both helpful and unhelpful. The latter may prove potentially unhelpful to an individual's physical and psychological health. Adolescents and young adults (AYA) with cancer can be particularly affected by the social interactions related to cancer, as they can be dealing with both a serious illness and normal developmental challenges. The overall study aims to form a comprehensive and complete model of all interactions relevant to AYA survivors and cancer. Once I have received everybody's responses, the data will be analyzed to create a map of how closely these interactions relate. The concept is the same as a geographical map that shows in physical space how close two towns are. This is the second of three studies aimed at identifying the psychosocial interactions of this group and the impact these might have on their development. It is believed that a better understanding of AYA patients' psychosocial experiences will enable family, friends and health professionals to provide more positive support for young people with cancer.

What is involved?

The overall study is divided into three smaller studies, and this is the second of the smaller studies. This study involves a card-sort activity, where you will be provided with approximately 80 small cards with different types of responses or interactions printed on each. The task requires you to sort these cards by similarity. The task will take about an hour and can be done at your convenience, even in front of the TV if you like.

I am looking for 30 participants - between ages **16 and 25** - to talk to. Participants **need to have completed treatment**, ideally around 6 months to 3 years ago.

As a reimbursement for your time and to thank you for participating, a $20 supermarket voucher will be provided for all participants. It would be greatly appreciated if you could complete the task and **return the participant pack using the return envelope within two weeks of receiving the pack**. However, I am grateful to receive the pack whenever you are able to complete the task, up until the end of August.

Please note, for your own safety if you are currently experiencing a mental illness, or have significant ongoing cognitive effects as a result of treatment, you will not be eligible to participate in this study. If you have any questions about this please contact myself, Dr. Baken or Dr. Ross.

Benefits and risks:

There are a few possible benefits and risks involved if you choose to participate in this study. Benefits may include some relief from sharing your experiences, which could help others. Your participation will help tremendously, not only towards my learning and research, but also hopefully for the benefit of others. Risks may include feeling upset or distressed about your experience with cancer. It is our responsibility to ensure that you are cared for should you become upset, and if this is the case we can refer you to your GP.

About your information:

All information gathered (e.g. consent forms, recordings and any notes taken during interviews) will be kept confidential and your responses will remain anonymous. Only you, my supervisors and I will have access to these and they will be stored in a locked cabinet in Dr. Don Baken's office and retained for review purposes. After 10 years, this information will be destroyed. The response forms will be kept separate from consent forms. When I write up the thesis, your identity will be kept anonymous and no identifying information (such as your name or location) will be included to ensure your privacy. Your decision to participate in this research will be kept confidential. This data will not be used in further studies after the completion of my thesis.

When the study is complete, you can choose to receive a summary of the research findings (you can indicate this on the consent form). I will be available to discuss these results with you if you wish.

Your rights:

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

- Withdraw from the study at any time, with no explanation required and no disadvantage
- Ask any questions about the study at any time during participation
- Be given access to a summary of the project findings when it is concluded

Who to contact:

If you would like to know more, please do not hesitate to contact me directly, or you can reach my supervisors with any queries or concerns:

- Nicole Cameron – nicolecameronresearch@hotmail.com or [redacted]
- Dr. Don Baken - D.M.Baken@Massey.ac.nz or 06 356 9099, x 81886
- Dr. Kirsty Ross - K.J.Ross@Massey.ac.nz or 06 356 9099, x 84968

If you want to talk to someone who isn't involved with the study, you can contact an independent health and disability advocate on:

Phone:	0800 555 050
Fax:	0800 2 SUPPORT (0800 2787 7678)
Email:	advocacy@hdc.org.nz

You can also contact the health and disability ethics committee (HDEC) on:

Phone:	0800 4 ETHICS
Email:	hdecs@moh.govt.nz

This study has been reviewed and approved by the Central Health and Disability Ethics Committee on 8th June 2016 based on the expedited review pathway – application 16/CEN/54. If you have any questions about the conduct of this research please contact the Health and Disability Ethics Committee on 0800 4 ETHICS or email – hdecs@moh.govt.nz

MASSEY UNIVERSITY
COLLEGE OF HUMANITIES
AND SOCIAL SCIENCES
TE KURA PŪKENGA TANGATA

A model of the psychosocial interactions of Adolescent and Young Adult (AYA) cancer survivors

PARTICIPANT CONSENT FORM - INDIVIDUAL

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

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

☐ Yes, I would like to receive a summary of the overall findings of this study.
Please mail/email a copy of the findings to: ______________________________
____
____

☐ I would like to be contacted to participate in future research as part of Nicole Cameron's studies, including a further study that will take place later this year.

Full name (printed): ____

Age: _______ **Ethnicity:**____

Gender: ______________________________ **CanTeen member (circle one): Yes / No**

Type of cancer: ____

Signature: ________________________ **Date:** ______________________________

Appendix J: Participant instruction and answer sheet

A model of the psychosocial interactions of Adolescent and Young Adult (AYA) cancer survivors

This participant pack includes the following:

- Information sheet and consent form
- Instruction and answer sheet
- Item cards
- Return freepost envelope

Once you have completed the task (preferably within 2-3 weeks of receiving this pack) please return all of the above except the information sheet and the gift card in the return envelope, at your nearest post office/box. Don't forget to tear off the consent form at the back of the information sheet to return (you may keep the information sheet if you wish).

If you would like to discuss anything related to this study, or if you have any questions please don't hesitate to contact me at: nicolecameronresearch@hotmail.com

Thank you kindly for participating!

A model of the psychosocial interactions of Adolescent and Young Adult (AYA) cancer survivors

Instruction Sheet

About this Task: We use the acronym, GOPA to describe the four steps involved: **G** = Group, **O**= Opposite, **P** = Partition, **A** = Add.

The entire exercise will take about 60 minutes (please spend about 5 minutes working through these guidelines).

There is a YouTube video to assist you with completing the task. If you choose to watch it, please read through these instructions first. The link is here: https://www.youtube.com/watch?v=thJwvvYbbBo or search "card-sort task fruit edition" in the YouTube search bar (the author name is Nicole Cameron).

Note: if you do become distressed while completing this task, please contact either CanTeen or your GP.

Getting Started

In front of you, there should be a set of item cards (please shuffle these before starting), a record sheet for entering your responses, a pen or pencil and these instructions.

Start by looking over the record sheet to identify the location of each step's response section. You can read over the summary notes on the record sheet now to get a feel for what each step asks you to do.

Find a large flat surface to work at. It is easiest if you have about a metre of space on which to spread out the cards and groupings. Each item represents an observable interaction shown by one person in the context of a two-person interaction (for example, within a conversation).

Please remember the aim is not to decide whether the interaction is helpful or not, but rather simply to group similar interactions.

Step One – Grouping

Take the shuffled card-item deck. Read the top card's statement and place it at top left of your working space so you can still see what it says. Then read the second item and make a decision. Does that second item belong in the same general group as the first one, or should it be placed into a new group? A "group" consists of those items you think are in some way similar, belonging to the same general family. If you think it belongs within the same family group then place the second item immediately below the first one (families run down, as columns). However, if you think the second item is unrelated and would belong in a new family, then start a new column by placing that item beside the first one, to the right. Any reasonable type of relationship is acceptable when deciding about a family's membership. You only need to justify family group relationship criteria to yourself.

Now, go ahead and place all the items into various family groups. As soon as you set out a few items this will begin to make sense. Try to make up between 8 and 16 families but with no more than 7 members in each one. A family can have just one item member if there are no apparent relations.

Record your answers. When you are satisfied these family groups make sense (and you may have to move the items around to firm these up) then print the numbers from each family onto the lines provided on the response page below. For this task, each family's item numbers will be printed onto a separate row. The top line has an example with a 7-item family group, namely: 14, 5, 21.... (Please print neatly).

Step Two – Opposites:

This time, look over the whole families and form in your mind a common theme for each one: what makes the items in each family stick together. Remember, for this step we are focusing upon whole families and not separate items.When scanning these families look for those that seem to be "opposites", at the extreme from each another. We find that in any item set there are generally two or three sets of quite different families.

Record. When you find a pair of opposites, enter onto the response form spaces provided any one item number selected from each of those two groups (the reason for entering only one item number is straightforward, because the whole families have been described in step one above then any one item number from a single family group will stand for the whole group).There is space to provide for up to six sets of family opposites. Try to find at least two.

Step Three – Partitioning (sub-dividing)

Using the groups from step one, for any family with 3 or more members it may be possible to find sub-groups within each whole family. Families with only 1 or 2 members do not have subgroups (Note: the video has an error where one group of 2 items is divided – please remember that this is a mistake). Do keep families intact; **do not** move individual items between families.One way to do this is to rearrange items within each family so subgroup members are kept together, leaving a small gap between them. In some cases there will be no subgroups because a family group is made up of very similar items. However, in most cases there will be some slight differences and it's these differences we want to know about.

Record. When sub-family groups have been formed use brackets on the recording form to show what they are. For all families that do have sub-groups, rewrite all item numbers on exactly the same line as in step one but this time use brackets to indicate how sub-groups are formed. Our example shows the use of brackets.

Step Four – Adding

This time we are asking you to merge similar family groups together. Go right back to the original family groups created in step one, above. Survey these whole families again (as was done in step 2). This time though the idea is to join families up, one pair at a time. Find the two most similar families. Then physically shift a whole family's items onto another one every time a merger occurs. This way it is clear which item-families have been joined up. It is possible to add onto a previous merger. But once a merger has occurred it cannot be undone. Several families will not join up because they are so different from each another. In general though at least 3 family mergers may be found.

Record. For recording purposes, as each merger occurs indicate on the response page spaces provided a single pair of item numbers, selecting any one item number to represent each family being joined together.

Response Sheet for Card Sort

Step One – Grouping

Make up **at least 8 (and up to 16)** different groups of similar items with **no more than 7** items per group. A group may have a single item. Keep each group's item numbers on the same line. **Please print neatly**. Do NOT number groups, rather record the item numbers from the top left-hand corner of each card.

Example: 7 22 1 43 78 12

____

____

____

____

____

____

____

____

Step Two – Opposites

Look over the step 1 groups to find which are the most different. Record these "opposites" by entering any one item number from each group on the spaces below. Try to find at least two sets of opposites. Use your own judgment. Leave the item groups intact. Do NOT move items around.

Opposite set 1: ____, ____# Opposite set 2: ____, ____#

Opposite set 3: ____, ____# Opposite set 4: ____, ____#

Opposite set 5: ____, ____# Opposite set 6: ____, ____#

Step Three – Partition

Copy all numbers from Step 1 onto the same line, but this time put item numbers within brackets. These brackets will show sub groups; that is how the most similar items go together. A sub group may have a single item within brackets.

Example: (12 43 22) (1 7) (68)

____

____

____

____

____

____

____

____

____

Step Four – Adding

This time join together the most similar groups in Step 1. Physically place these similar Step 1 item groups together and enter any one item number from each joining group onto the spaces below. Only some groups will join up, many will not. Try to make at least two merges. If there are more than three, continue showing item pairs.

merger a) _____, _____#

merger b) _____, ______#

merger c) ______, _______#

merger d) _____, _____#

merger e) _____, ______#

merger f) _______, _______#

Thank you for your time and participation!

Appendix K: Dendrogram

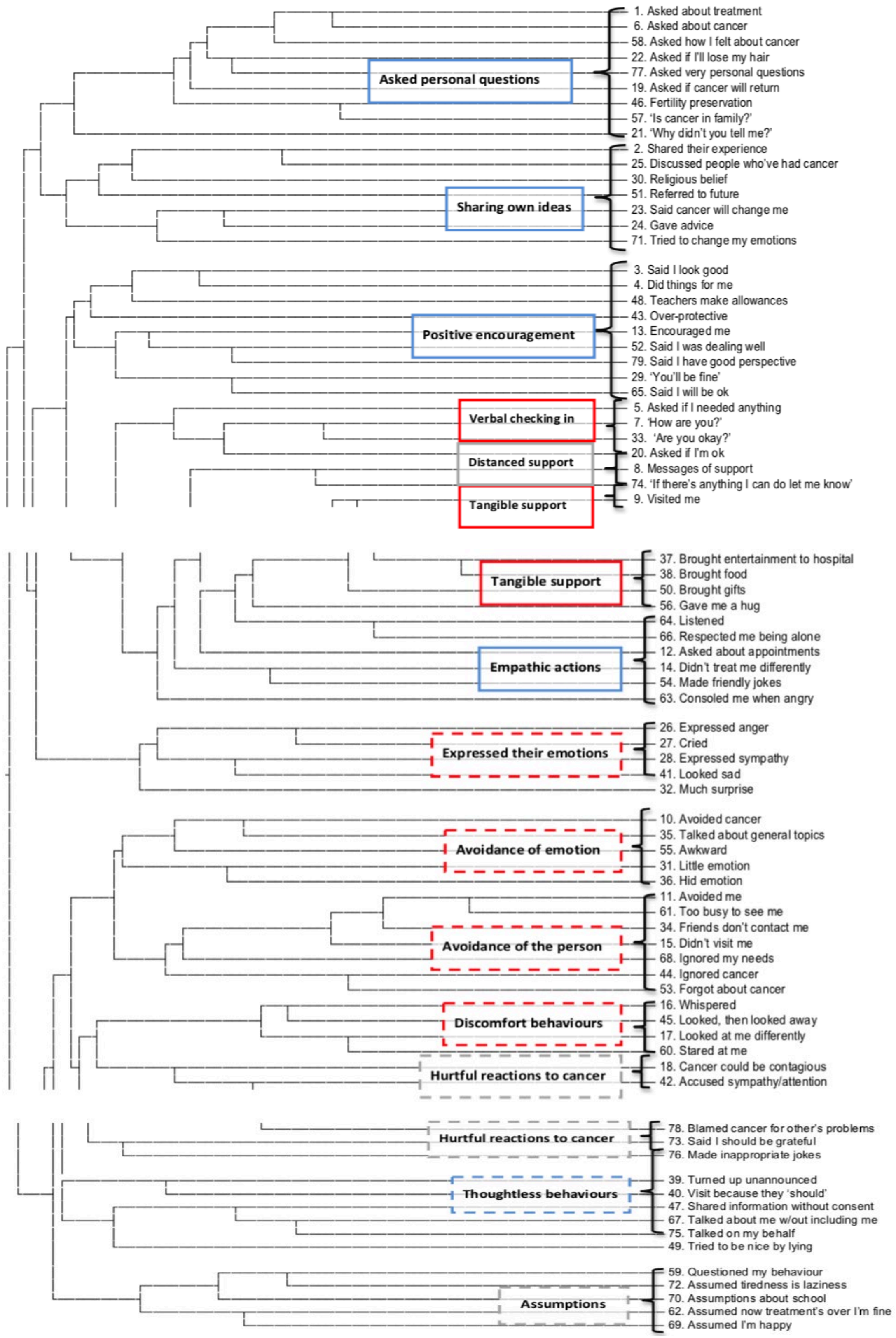

Figure 1. Dendrogram with item numbers and descriptions, and cluster labels. Coloured lines around each cluster name correspond to the shapes representing each cluster in Figures 2 and 3. Solid lines correspond to a solid shape and dotted lines correspond to a hollow shape.

Appendix L: List of clusters and dimensions

Cluster items	**Cluster name**
1. Asked about the details of treatment 6. Asked me about cancer 58. Asked me how I felt about cancer 22. Asked me if I'm going to lose my hair 77. Asked very personal questions 19. Asked me if cancer is going to come back 46. Brought up fertility preservation 57. Asked me if cancer is in my family 21. Asked, "Why didn't you tell me?"	**Asked personal questions**
2. Shared their own experience with cancer 25. Told me about people they know who have/have had cancer 30. Expressed religious belief in my survival 51. Referred to my future 23. Told me cancer is going to change me 24. Tried to give me advice 71. Tried to change my emotions towards cancer 32. Reacted with much surprise	**Sharing own ideas**
3. Commented that I look good 4. Did more things for me (opening doors, making cups of tea etc.) 48. Teachers said they would make allowances for my illness when marking 13. Encouraged me to keep going 52. Told me how well I was dealing with having cancer 79. Commented that I have a good perspective on cancer 29. Told me "You'll be fine" 65. Told me that I will be okay	**Positive encouragement**
5. Asked if I needed anything 7. Asked, "How are you?" 33. Asked me, "Are you okay?" 20. Asked me if I'm okay	**Verbal checking in**
8. Sent messages of support 74. Said "If there's anything I can do just let me know"	**Distanced support**
9. Visited me 37. Brought things to entertain me in hospital 38. Brought me food 50. Brought me gifts 56. Gave me a hug	**Tangible support**

64. Listened to me 66. Respected me when I wanted to be alone 12. Asked how appointments went 14. Didn't treat me any differently 54. Make friendly jokes about cancer 63. Consoled me when I am angry	**Empathic actions**
26. Expressed anger 27. Cried 28. Expressed sympathy towards me 41. Looked sad towards me	**Expressed their emotions**
10. Avoided talking about cancer 35. Talked to me about general topics (excluding cancer) 55. Acted awkwardly around me/didn't know what to say 31. Reacted with little emotion 36. Hide their emotion from me	**Avoidance of emotion**
11. Physically avoided me 61. Told me they are too busy to hang out with me 34. Friends no longer contacted me 15. Didn't visit me in hospital 68. Ignored my needs 44. Ignored the fact that I had cancer altogether 53. Forgot I had cancer	**Avoidance of the person**
16. Whispered about me 45. Looked at me, and when I turn around they looked away 17. Looked at me differently 60. Stared at me	**Discomfort behaviours**
18. Expressed the idea that cancer could be contagious 42. Said I was trying to get sympathy or attention from having cancer 78. Blamed my cancer for other people's problems 73. Told me I should be grateful	**Hurtful reactions to cancer**
76. Made inappropriate jokes 39. People turned up unannounced to see me 40. People visit me because they feel they should (not because they want to) 47. Shared information about me with other people without asking me first 67. Talked about me without including me in the conversation 75. Talked on my behalf without letting me answer	**Thoughtless behaviours**

59. Questioned my behaviour 72. Assumed my tiredness is attributed to laziness 70. Either assumed I missed or didn't miss school 62. Assumed that now treatment is over I am fine 69. Assumed I am happy	**Assumptions**

Dimensions:	Poles	Polar meanings
X: **Emotional Response**	+ -	Avoidance/Discomfort Support
Y: **Empathy**	+ -	Empathic actions/Encouragement Thoughtlessness

Dimensions	**Poles**	**Clusters within poles**	**Items**
X: Emotional response	Avoidance/Discomfort	Avoidance of the emotion Avoidance of the person Discomfort behaviours Expressed their emotions	10, 35, 55, 31, 36 11, 61, 34, 15, 68, 44, 53 16, 45, 17, 60 26, 27, 28, 41
	Support	Verbal checking in Tangible support	5, 7, 33, 20 9, 37, 38, 50, 56
Y: Empathy	Empathic actions/ Encouragement	Empathic actions Verbal encouragement Sharing own ideas	64, 66, 12, 14, 54, 63 3, 4, 48, 13, 52, 79, 29, 65 2, 25, 30, 51, 23, 24, 71, 32
	Thoughtlessness	Thoughtless behaviours Asked personal questions	76, 39, 40, 47, 67, 75 1, 6, 58, 22, 77, 19, 46, 57, 21

Appendix M: Split hemisphere graphs

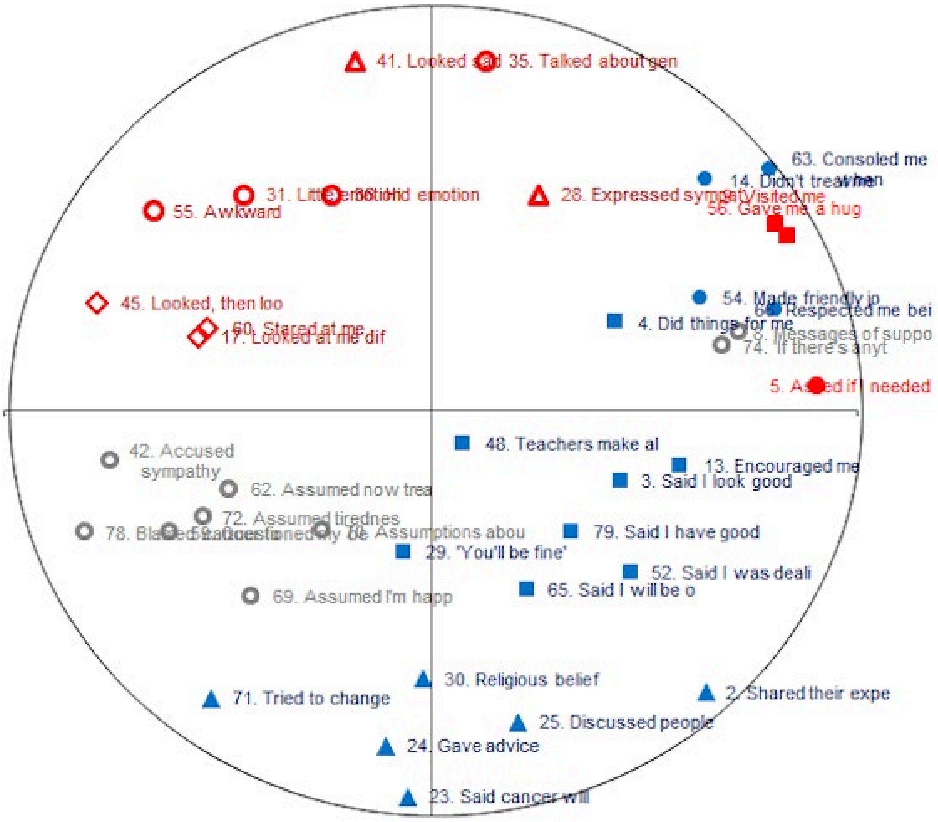

Figure 2. Split-hemisphere view of model shows the *Emotional Response* (red symbols) and *Empathy* (blue symbols) dimensions. Grey items do not relate to either dimension. Solid blue squares= *Verbal encouragement* cluster, solid blue triangles= *Sharing own ideas*, solid blue circles= *Empathic actions*. Hollow blue circles= *Thoughtless behaviours* cluster, hollow blue squares= *Asked personal questions*. Solid red circles= *Verbal checking in* cluster, solid red squares= *Tangible support*. Hollow red circles= *Avoidance of emotion* cluster, hollow red squares= *Avoidance of the person*, hollow red diamonds= *Discomfort behaviours*, hollow red triangles= *Expressed their emotions*.

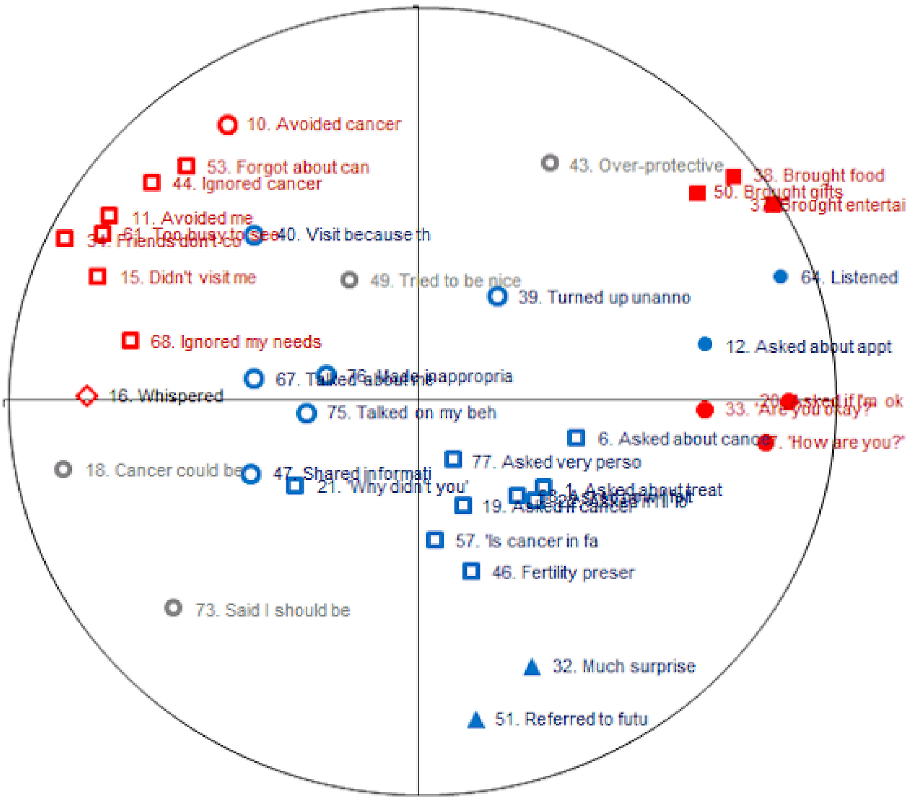

Figure 3. Split-hemisphere view of model shows the *Emotional Response* (red symbols) and *Empathy* (blue symbols) dimensions. Grey items do not relate to either dimension. Solid blue squares= *Verbal encouragement* cluster, solid blue triangles= *Sharing own ideas*, solid blue circles= *Empathic actions*. Hollow blue circles= *Thoughtless behaviours* cluster, hollow blue squares= *Asked personal questions*. Solid red circles= *Verbal checking in* cluster, solid red squares= *Tangible support*. Hollow red circles= *Avoidance of emotion* cluster, hollow red squares= *Avoidance of the person*, hollow red diamonds= *Discomfort behaviours*, hollow red triangles= *Expressed their emotions*.

Appendix N: Research case study

The psychosocial interactions of Adolescent and Young Adult (AYA) cancer survivors and the possible relationship with their development

This case study was completed during the period of an internship as part of a Doctor of Clinical Psychology, and represents the work of Nicole Cameron under the supervision of Kirsty Ross (and others).

In accordance with the Code of Ethics for Psychologists Working in Aotearoa/New Zealand the privacy of participants is maintained by utilising pseudonyms and adapting identifying information.

This study has been reviewed and approved by the Central Health and Disability Ethics Committee New Zealand on the 3rd August 2015 based on the full review pathway – application 15/CEN/76. Informed consent was obtained from all individual participants included in the study.

Name: Nicole Cameron, Intern Psychologist, Child Development Service, Palmerston North

Student ID: [redacted]

Supervisor: Kirsty Ross, Senior Clinical Psychologist, Massey University Psychology Clinic, Palmerston North

Word Count: 5617 (excluding references)

Candidate:____________________________

Supervisor:____________________________

Date: 24th November 2017

The psychosocial interactions of Adolescent and Young Adult (AYA) cancer survivors and the possible relationship with their development

Nicole Cameron, Dr. Don Baken, Dr. Kirsty Ross, & Dr. David Bimler
Massey University, Palmerston North, New Zealand

Abstract

Adolescents and Young Adults (AYA) with cancer may be particularly affected by social interactions, as they can be grappling with both a serious illness and normal developmental challenges. The present study aimed to explore interactions relevant to AYA survivors and cancer, and investigate whether certain interactions are experienced as more and less helpful. As development is important for this age group, it is essential to consider the impact that psychosocial interactions related to cancer are perceived to have on their development. Ten semi-structured interviews with AYAs (16-25 year olds) were conducted, with questions pertaining to their psychosocial interactions and any developmental effects from having cancer. Five follow-up interviews were conducted approximately twelve months later. Thematic analysis identified a range of themes including: the importance of personal privacy and controlled sharing of information, independence, identity formation, positivity, acknowledgement of cancer vs. being treated normally, and receiving support instead of supporting others. In the one year follow-up interviews, half of these themes remained constant, however the personal privacy, independence and supporting others themes changed. Overall, social support, social interactions and developmental stage appear to influence the overall cancer experience. Development appears to be impacted by cancer for both adolescents and young adults, but this impact changed over a one year period. It is believed that a more comprehensive understanding of AYA patients' psychosocial experiences related to cancer will enable those who interact with this group to provide more positive support through their interactions for the individuals involved.

Background

Adolescents and Young Adults (AYA)

According to the Adolescent and Young Adult Cancer Incidence and Survival in New Zealand report, between 2000 and 2009 there were on average 160 new cases of cancer in adolescents and young adults[2] each year in New Zealand (Ballantine & Sullivan, 2013). Furthermore, cancer is the leading cause of non-accidental death in AYAs in developed countries (Padhye & Gabriel, 2013), indicating the impact of the illness for this age group. Social support is important because it has been shown to impact on AYAs' treatment adherence and this in turn may influence short- and long-term health ourcomes (McGrady et al., 2016). There are an increasing number of studies that show that the psychosocial issues facing AYA survivors are unique to this age group, separating them from those issues present in childhood or adult cancer survivors (D'Agostino & Edelstein, 2013). Literature demonstrates that AYAs experience numerous psychosocial effects including the impact on their identities and development, and this is currently a focus for research internationally (Patterson et al., 2015). Additionally, research has shown a link between distress and unmet health, physical and psychological needs for AYAs (Dyson et al., 2012), as well as demonstrating developmental effects of cancer, such as the effect on AYAs education, sexuality, family planning, and their identity formation (Richter et al., 2015). Thus, the psychosocial wellbeing of AYAs and their social interactions can make a considerable impact on their experience with cancer.

Development

Human development theory lends itself to the exploration of developmental and psychosocial effects on AYAs. Erikson distinguished between adolescence and young adulthood as the difference between fidelity and love (Kivnick & Wells, 2014), and that this is when the individual experiences an identity crisis (Erikson, 1970a). Thus, the AYA stage is perceived as a time of substantial individual growth and change.

Identity formation can be a key developmental process for young people and this process has been identified as more challenging for AYAs due to the possible conflict between the cancer and survivor identities (Jones et al., 2011). Gibbs (Gibbs, 2002) studied the psychosocial effects of cancer on young adults looking specifically at the

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[2] The term AYA is interpreted more or less liberally among different countries, with some research separating adolescents (anywhere between 12-19) and young adults (anywhere between 20-39). For the purposes of this research, AYA refers to 16-25 year olds as this is within the more commonly accepted age range internationally.

effect on development in relation to Erikson's theory of development. In terms of identity, participants appeared to be incorporating survivorship into their identity, although some struggled with their autonomy, particularly those who felt they had partially lost this during the treatment process. Some survivors fought to find an appropriate place for cancer within their identities, and several survivors felt their identities had been altered so extensively that they felt distinctly different from their peers. In particular, facing thoughts about death and mortality clashed significantly with the 'normal' developmental stages of peers (Enskar & von Essen, 2007). Overall findings showed that survivors appeared embroiled in earlier developmental conflicts such as trust and autonomy, and were actually less concerned with identity than the comparison group (Gibbs, 2002). Gibbs (Gibbs, 2002) concluded that this discrepancy could occur because cancer can threaten an individual's fundamental understanding of the world, resulting in regression to earlier developmental challenges that they may have already surpassed. Similarly, Williams et al. (2013) identified regressional developmental stages in adolescent cancer survivors; however, they found that family structure and routine was likely to support adolescents to maintain their identities by enhancing control and predictability in their everyday lives.

Social Support

The developmental importance of social support for AYAs is evident in the literature. Decker (Decker, 2007) found family and peers were the most valuable sources of social support, particularly as adolescents often live with at least one other family member. For this reason family are often considered the main source of support, both practically and emotionally (Wakefield et al., 2013), although peers who have also experienced cancer are likely to be very valuable as well. While age-respective peers can be very helpful for AYAs, the developmental stage typical of adolescents can hinder their understanding of cancer (Wakefield et al., 2013) and could limit their empathy towards AYAs. A study by Zebrack, Chesler and Kaplan (Zebrack et al., 2010) looked at behaviours that were helpful and hurtful for AYAs to establish their effect on their overall well-being. Of the social support behaviours, positive attention (in the form of gifts or visits from others) and the promotion of normality were considered helpful, alongside the emotional and practical support from other AYA survivors because of their shared experience. Hurtful behaviours included negative or lack of attention, and denying or dismissing experience. Negative attention was further included as inappropriate comments, laughter or teasing, over-protective parents or feeling uncomfortable due to the approach of mental health professionals. Overall, participants confirmed the importance of interpersonal support, suggesting that social support - and negative behaviours -

can considerably impact their experience with cancer (Zebrack et al., 2010).

Social support from peers has been linked to positive affect in adolescent AYAs, and Wesley et al. (2013) suggest social support may encourage normal socialisation alongside increased positive feelings. One study identified that opportunities to meet other AYAs who had experienced cancer were rated as more important than support from family and friends, and connecting with other AYAs and peers in general also encourages a sense of group identity, a core developmental task common to young people (Zebrack et al., 2006).

The present study

Given the importance of social support for the AYA population it is imperative to more fully understand their psychosocial interactions. This study aims to delve into these interactions and explore whether any are perceived as more and less helpful as seen through the lens of the developmental stage of these young people. One year follow-up interviews were conducted to identify whether time and age affects AYAs' perception of their psychosocial interactions, and whether a one-year time lapse affects the developmental impact on these young people. Looking to gain a better understanding of how experiencing cancer interacts with the developmental stage of AYAs is an important pathway to offering the appropriate type of support to this population.

Method:

Recruitment

Participants were approached through CanTeen New Zealand (a non-profit organisation supporting young people with cancer) with the objective of recruiting ten members to participate in the study. Contact was made by the lead author to national and provincial CanTeen offices. CanTeen workers asked members if they wished to participate, and those who did contacted the lead author. Brief phone calls were then arranged with members to discuss inclusion critera and once it was established that criteria were satisfied, to organise an interview. Inclusion criteria stated all participants must be between 16-25 years, that treatment must have concluded at least six months previously and preferably within three years of participation. Nine participants were recruited through CanTeen. A press release was also circulated and one participant made contact after seeing a newspaper article that resulted from this. Participants either received information sheets through CanTeen or these were emailed prior to the interview, and consent forms were signed at the time of interview (one participant posted the form).

Procedure

Nine interviews took place in person, and one was conducted by telephone (at the participant's request). Interview questions were based on two main categories: psychosocial interactions, and developmental impacts of cancer. Interview questions were semi-structured, with questions regarding psychosocial interactions asking about: helpful and unhelpful responses to cancer from others, and advice for newly diagnosed AYAs. The developmental questions related to: identity, age of diagnosis, the meaning of cancer, and other developmental interruptions.

Participants

For developmental purposes the sample was split into an adolescent group (16-19) and a young adult group (20-25). The mean age of the younger participants was 17.5 years, and the mean age of the older participants was 23.2 years. Participants' overall mean age was 20.9 years, with an equal gender split. Of the ten participants, three described themselves as New Zealand European or Pakeha, one as New Zealand Maori, one as Tokelauan, two as both New Zealand European and New Zealand Maori, two as both New Zealand European and Cook Island Maori, and one did not disclose their ethnicity. Participants had been diagnosed with a heterogeneous group of cancers with three having been diagnosed with Leukemia, two with Lymphomas, two with a brain tumour and one particpant with each of Thyroid Cancer, Osteosarcoma and Sarcoma. Participants had undergone a range of treatments with eight having had surgery, seven chemotherapy, seven radiation therapy and three a stem cell transplant. The names of participants have been changed.

Follow-up interviews

These interviews were conducted approximately twelve months after the first interviews, and all eligible participants from the first interviews were emailed an invitation to participate. Five participants agreed to participate, including three female and two male, with a mean age of 21.8 years. One participant provided a written response to interview questions, two participants were interviewed in person, one over the phone and one via Skype. Interview questions mirrored those in the first interviews to measure differences in developmental impact and psychosocial interactions, and questions regarding changes in the last twelve months, and new disclosures were also included.

Analysis

All interviews were recorded (except the written account) and transcripts were analysed by thematic analysis (Braun & Clarke, 2006). According to Braun and

Clarke (2006), thematic analysis "is a method for identifying, analysing and reporting patterns (themes) within data" (p. 79). A number of general patterns were identified from the transcripts, evidenced in the sections below and categorised by the identified themes.

Results:

Initial interviews (2015)

Personal privacy and sharing of information

Participants spoke about the difficulty of maintaining personal privacy boundaries with parents and other family, or those visiting in hospital. A number of participants addressed their discomfort with sharing private details about their bodies with acquaintances or people they didn't know well – or when family members shared personal details without seeking permission to do so - and discussed how awkward it can become to avoid answering personal questions ("You can become a bit more of an object than a person there for a bit" (Robert)). However, while privacy was important to participants, they were largely aware that at times this came at the expense of others' speculation. Consequently, participants welcomed carefully-timed and respectful questions and preferred to be asked than for people to whisper, gossip or make false assumptions. There was a recognition among most participants that others were naturally inquisitive about cancer and their experience, and for some people they would not have known a young person to have had cancer before ("I'm okay with questions and okay with being open about it, I was sort of just asked straight away so that was good" (Matthew)). Therefore, participants shared information - when appropriately requested – to dispel myths and encourage a positive but realistic public understanding of cancer, and also to maintain their ownership of their personal information.

Independence

Young adult participants (those aged 20-25) spoke of experiencing newfound independence from their parents prior to cancer, only to discover that alongside the cancer diagnosis comes increased dependence on their parents. These participants found it difficult to again rely on their parents (or others in general), symbolic of a regression in their development. Such regression creates incongruency in developmental stages and distinguishes AYAs from their increasingly autonomous peers. Futhermore, a sense of loss occured for some participants when acknowledging that they required physical, emotional and financial support, despite having recently acquired (or started the process of gaining) autonomy. Erikson proposed that adolescence and young adulthood involved a gradual separation from parents towards independence and autonomy (Kivnick & Wells, 2014). Younger participants (16-19) also acknowledged their reduced independence, but most still lived at home and were fundamentally reliant on their parents before their diagnosis. One adolescent viewed this as a positive, saying “you’re still… really sheltered… you’re not expected to… shoulder everything like an adult” (Sarah).

Identity formation

While most participants made some reference to the impact of cancer on their identity, this appeared more profound in younger (16-19 year old) participants. Younger participants appeared more likely to express feeling that their personal identity and cancer had become merged due to others who “just all of a sudden think that me and cancer were the same thing” (Lisa). One high-school aged participant feared she would be known as “the girl with cancer” at her school for some time. It may be likely that adolescents are more susceptible to cancer impacting their identity formation due to their developmental stage, as well as the strong desire to fit in with peers – a desire characterisitc of the adolescence period. The ‘sick patient’ role threatens the young person’s ability to be perceived as ‘normal’, and consequently was rejected by participants. One older AYA participant reflected back on his experience and said, “You don’t get to find out who you are, and then suddenly you’ve got this label and you’ve been told who you are… You’re so much more than f***ing hospital beds and… short hair or no hair, you know?” (Jon). The young person can find themselves facing multiple self-perceptions of their identity, and the ‘cancer’ identity does not necessarily integrate easily with the identity the AYA was forming prior to cancer.

Older participants (20-25 year olds) also referred to the disruption of developmental trajectories, with one participant depicting the impact of cancer on identity as “your innocence, kind of stolen”, because “you miss out on growing up” (Jon). The effect of feeling as though AYAs have missed out “on growing up” may result in a sense of being rushed into adulthood, potentially preventing AYAs from experiencing crucial stages in their identity formation. However as young adults their identities were inclined to be more established than younger participants (16-19 years) because they had already navigated adolescence prior to diagnosis. In general, many participants acknowledged that cancer had contributed to who they were as people today, and this was not always viewed negatively. The conflict between attributing cancer to something that had made them stronger, but not something that dominated their identity, was a difficult paradox to negotiate.

Positivity

Experiencing cancer was reported to have a number of positive effects for participants. Revised priorities was a common theme among participants, with most identifying new purpose in life and the importance of surrounding themselves with supportive, positive people. Remaining positive about the cancer experience was commonly addressed (“every day is a good day” (Hannah)), and the majority of participants were adamant that it was imperative to “make the most of this s****y situation” (Jon) in order to mentally stay strong. The importance of remaining positive was exemplified by the statement that “the way that they see their situation is half of the fight … as bad as cancer is in itself, I find that it often brings out the best in people” (Matthew). Nearly all participants commented that they were enriched by their experience and stronger for it; however those who reported having more insight and viewed the experience more positively were also those who reported less negative social interactions. Nonetheless, embracing a positive outlook partially contradicts participants’ discussion of the substantial difficulties and challenges that cancer poses. This conflict is evident in the earlier quote by Matthew, where he resolves that perspective takes precedence over both the positives and negatives of the experience.

In many instances participants also commented that, despite experiencing developmental interruptions, they preferred to experience cancer as a young person rather than be faced with cancer later on in their lives. Participants described this as, “probably the best time that I could have cancer unfortunately, because … I’m still young enough not to have other people relying on me” (Jon) and “… you have that support system … you’re still under the wing of your parents” (Sarah). This outlook represents an advanced developmental perspective that demonstrates the remarkable strength and resilience of participants toward coping with developmental impacts, as they are able to reflect on both positive and negative aspects of their experience as a young person.

Acknowledgement vs. being treated normally

Most participants stated that they did not want to be treated differently, or to be treated in a way that failed to distinguish between themselves as people and cancer. It was important to participants that they were treated as the same person before, during and after treatment. One participant portrayed the people who didn’t treat her differently as “… the anchors who just didn’t change. And everything else did. So it was good to have those people” (Sarah). Being treated the same also helped the individual to move away from the ‘sick patient’ role, an important factor when considering AYA identity. Conversely, participants also acknowledged that it was helpful in work, school and social settings, as well as at home, when others treated them with sensitivity towards their health. This was particularly true soon after diagnosis through until treatment concluded, as this was the period where participants tended to be most physically and psychologically vulnerable. The conflict between AYAs wanting to be treated as separate entities to cancer, yet also requiring others to behave considerately towards their situation, was a tension present in most of the participants' discussions.

Peer responses within the school environment were distinctly different from other responses and involved some of the most unhelpful interactions. Staring and inappropriate or hurtful comments were more common for those participants at school, and some participants also commented that their friends stopped inviting them to social events. One participant described this as, "I lost quite a lot of friends cause they'd say they were my friends and then they'd just talk about me behind my back, or be too scared to talk to me" (Emily). Older participants (who were not diagnosed whilst in school) tended to be more understanding in their response to others' reactions and behaviours. This may be partly due to the insight developed in older AYAs, by which a number recognised the difficulty others have with knowing what to do or say, predominantly related to cancer itself rather than themselves personally. Thus, peer responses differed substantially between the younger and older participant groups, and were interpreted differently too, in keeping with developmental stage. Younger adolescents had an ego-centric perspective about the impact on them; young adults were able to consider the other's perspective as well as the effect on them.

Support instead of supporting others

Participants at times distinguished between support received and instances where they were required to support others. Literature on adult cancer survivors has highlighted the finding that survivors can experience overwhelming emotional reactions from others (Yoo et al., 2010), a feeling that was also experienced by these AYA participants. Many participants hoped others would be interested to know how they were coping rather than convey their own emotions towards the AYA. One participant disclosed that "nobody actually asked me what I thought of cancer when I got diagnosed" (James), expressing that it is important for family and friends to check how the AYA is and what their thoughts are before responding with their own opinion.

When participants were asked what they would like to change about responses to AYA cancer, it generally revolved around enhancing others' understanding of cancer and the positive prognoses for most. A number of participants commented on the misperception that a cancer diagnosis is a death sentence, and participants indicated that it would "definitely be good for people to understand that (cancer is not a death sentence), to not just hear cancer and automatically assume the worst" (Matthew). The emphasis on others' positivity would enable AYAs to focus on processing their own emotions rather than supporting others with theirs, something young people experiencing cancer may be unable to cope with.

Follow-up interviews (2016)

Twelve months on, two participants had transitioned from high school to university, two had returned to work, and one had transitioned from university to work. Therefore, each of their circumstances had changed since their first interviews, in turn influencing their interactions and the impact of cancer on their development. Upon analysis of the data, three of the above themes appeared to have remained constant, and three themes appeared to change. *Personal privacy and sharing of information* altered substantially for the two participants who were now attending university, as they appeared to struggle with deciding when, how and if to disclose their experience to others. As both these participants were diagnosed in high school, they had lost control of disclosing cancer to others at diagnosis, but at university with a new peer group who were unaware of their health history, they had complete control over sharing this information, which proved to be a daunting experience for these young people. However, these participants were pleasantly surprised at the accepting response others had when they did choose to disclose their experience. Two older participants spoke of their new-found comfort speaking with others about their experience, describing this as a way of giving back to others who are in some way affected by cancer. In turn, by sharing their experience they also inadvertently shared the message that cancer was not necessarily a death sentence, and that positive outcomes such as personal growth were also possible.

Independence was no longer such an issue for all participants, as they regained independence from their parents and returned to work or university, or travelled. Changes in independence appeared to occur very quickly over the one year between interviews, a potentially positive sign for some AYAs going forward. It is likely that this increased independence from parents allowed AYAs to work towards establishing their post-cancer identity, especially allowing them to identify more as a young adult rather than a child or adolescent.

Support instead of supporting others also changed, as older participants had a larger capacity to support others, and to give back to others affected by cancer, than when they were interviewed a year earlier. Younger participants encountered more support from peers than last year, with new disclosures, and experiencing their peers as more mature at university. It may also be likely that the younger AYAs' perception of their peers' responses changed over the one year period, with their increased control over which information their peers were told. Perhaps because their peers were not privy to the high school 'rumour mill', and were more often informed of the cancer by the AYA themselves than their high school peers, their responses (and reflectively, AYAs' positive interpretations of these responses) were more accepting and supportive.

Positivity remained constant as a theme and was ever present for all participants. This related to both participants' own experience of cancer and their outlook on life. *Identity formation* – participants appeared to experience the same paradox as was present twelve months previously, where they acknowledged that cancer had contributed to who they were, but it didn't define them. Compared with the previous year however, there was less tension between their 'old' and 'new' (post-cancer) selves. Lastly, *Acknowledgement versus being treated normally* also stayed constant, as it was still important that cancer was acknowledged, but that participants were still treated normally.

Participants noted that the most helpful aspect of others' responses in the last year was acceptance and coming across as genuine, and acknowledging that cancer was a big part of their lives. However, all follow-up interviews showed an increased emphasis on cancer being slightly in the background rather than the foreground. For all participants, cancer continued to inspire their lives and meant they were more appreciative of life in general. Participants also noted increased inner strength, self-awareness, and determination, alongside a strong message of personal strength and growth.

Conclusions:

From these findings it appears that AYAs experience a range of issues related to their psychosocial interactions with others, particularly in the first interviews. This is understandable as AYAs were closer to their diagnostic and treatment experiences when first interviewed. Social and practical support from family, friends and others appears to be immensely beneficial to individuals and their overall outlook on the cancer experience. This reinforces the importance of social support and acceptance for AYAs, and supports the findings of Corey et al. (Corey, Haase, Azzouz, & Monahan, 2008) and Teall et al. (Teall et al., 2013). Participants' positive feedback on the support and understanding from others also supports the findings of Zebrack et al. (Zebrack et al., 2010). It appears from the current study that interactions that convey acceptance, empathy, and understanding and those that provide (or offer to provide) practical and emotional support are most helpful to AYAs. Unsurprisingly, most participants expressed that avoidance and other behaviourally discriminating interactions (such as staring, exclusion and isolation, and being treated as fragile) were largely unhelpful. These initial findings appeared to be reinforced by participants at one year follow-up interviews; however, fewer unhelpful interactions were reported at follow-up, suggesting either participants had less cancer-related interactions or they interpreted interactions differently as time post-cancer increased. It is also possible that their interactions changed as AYAs' peers matured over a year. Therefore, psychosocial interactions, or at least the perception of these, do appear to change over time, and as AYAs and their peers age (particularly with substantial developmental and environmental changes such as beginning university and returning to employment).

It appears that there is some conflict between interactions that endeavour to treat AYAs the same (such as avoiding pity) and those that treat AYAs differently (for instance, inquiring about treatment). This conflict seems to underpin a fundamental tension where AYAs wish to be both acknowledged as strong and invulnerable, and where they hope that others understand the severity of the disease and accommodate their needs. It is likely that this tension also relates to AYAs' incorporation of cancer within their identities, in the sense that they struggle to include the 'cancer survivor' or 'patient' identity into their previously increasingly autonomous, healthy and perhaps strong selves. After one year the latter tension is less apparent, so it may be that the closer the young person is to their cancer experience, the more relevant this tension is. Possibly, as the AYA becomes healthier and experiences fewer physical effects from cancer and its' treatment, the young person identifies less with the 'patient' identity and more with the 'survivor' identity. As cancer moves to the background of their focus and re-integration with everyday life continues, they are able to establish their post-cancer identity and what it means for them individually to live beyond cancer.

Cancer affects the normal developmental processes that young people experience, and forces AYAs to be faced with discordant developmental issues such as mortality and increased dependence. Young people's interpretations of psychosocial interactions appears to be related to their developmental stage and how well they are able to understand the world around them. In particular, AYAs' insight and perspective seems to be linked to the number of recalled negative interactions and their developmental stage. Increased insight or perspective might occur as young adults and their peers may become less egocentric in their worldview compared with adolescent AYAs and their peers. The follow-up interview findings support this idea, as younger AYAs find their university peers more supportive than in high school, suggesting increased maturity as their peers transition to young adults. In addition, it should be noted that the older AYAs generally had increased insight into their situation at the first interviews than the younger AYAs did, reflective of the changes in development as these young people grew.

These results show that key elements of the developmental process are impacted by cancer, as previously suggested by existing literature, although this varies based on factors such as age of diagnosis, physical impact, and attendance at school. In addition, a one year time lapse does appear to effect the developmental impact of cancer, as this impact lessens or changes its focus as AYAs change environments and transition to young adulthood, or adulthood.

Clinical Implications

In practice, it is recommended that health professionals discuss the potential responses from others with newly diagnosed AYAs, to work towards preparing them for these reactions and managing their own responses. Clinicans should be aware of the substantial role that development plays in the psychosocial effects on AYAs and factor this in when assessing and treating young people with cancer. Consequently, AYAs should be offered a referral to a mental health or skilled support worker to provide psychological or emotional support and reduce the likelihood of the young person developing ongoing psychological effects from cancer. Furthermore, it is helpful for clinicians to consider taking a systemic approach, by offering to talk to family, close friends or others about communication strategies and aspects such as privacy and boundaries around information.

Future directions

Future research needs to identify the needs versus experiences of interactions with each of these groups, and to work towards a more comprehensive understanding of how development is impacted by cancer at a young age. Additionally, studies that look at any changes in AYAs' perspectives over time would allow researchers to gain a better understanding of how growing older affects the way young people view cancer and the related interactions.

Limitations

The small number of participants should be considered when interpreting these results. This number were selected due to the exploratory nature of this study and to establish a sample of AYAs' experiences but it will be important to confirm the findings with a larger sample. Additionally, nine out of the ten participants were recruited through CanTeen. It should be considered that CanTeen provides extensive support to their members and therefore the experiences of non-CanTeen AYAs may differ.

This study has identified several key interaction issues relevant to AYAs with cancer. It appears that there are common helpful and unhelpful interaction types, although there is some variance of this based on young people's developmental stage. These findings suggest that the meaning and experience of interactions from AYAs' perspectives may change over time, so communication from others identifying what is helpful or unhelpful for them individually is crucial. It is hoped that these results will assist those who interact with AYAs to provide beneficial support for the individuals involved.

Self-reflection on clinical practice implications

The interviews described in this article were my first experience of interviewing in a psychology capacity. I had considerable anxiety before the first set of interviews in 2015, and some (although less) anxiety for the follow up interviews in 2016. These interviews taught me a great deal about talking to clients, or research participants, for my internship in 2017. I am grateful for the humanistic focus they gave me, the emphasis on the person sitting in front of me instead of my interview agenda. I was particularly concerned about my emotional reaction in the first interviews, but again this prepared me well for the internship. I learned the benefits of showing my own human 'face', and not just the professional persona in the room. I think this led to slightly more confidence with addressing difficult topics with clients in my internship, and not shying away when a client showed their emotion with me. Lastly, the most important aspect that I learned from these interviewing experiences for my internship was the power of rapport and emotional connection. Clients (and these participants) disclose their biggest fears to us as professionals, and in doing so they trust we have the skills to respond appropriately. Even in times where I felt unsure of the 'right' reaction, I tried to focus on their experiences and how this must feel to be placed in their position. Valuing and respecting the client, no matter how far we deviate from the interview schedule or treatment plan, was an enormous lesson I learned in conducting these interviews. I think this skill is at the heart of being a clinical psychologist, to first be a human, and secondly be a professional.