



A facilitated peer support and education based survivorship group for adolescents and young adults living with cancer.

BUILDING CANCER SUPPORT GROUPS

Final Report 2009

onTrac@PeterMac
VICTORIAN ADOLESCENT & YOUNG ADULT CANCER SERVICE



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Acknowledgements

This project was funded by Cancer Australia through the Building Cancer Support Groups.

The project team and onTrac@PeterMac acknowledge and gratefully appreciate the contribution of many individuals who have assisted throughout this project. Our particular thanks go to the young people who shared their experiences, insight and wisdom to assist us in improving the delivery of age appropriate interventions for adolescents & young adults living with cancer.

We would also like to acknowledge those young people who, since the completion of the group have relapsed in their disease and are undergoing further treatment or who are no longer with us.



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Project Time :

February, 2007 – June, 2009



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1.1 Introduction

Funding for this project was received through Cancer Australia's Collaborative Cancer Support Networks Grants program aimed at strengthening the capacity, quality and availability of support networks for people across Australia affected by cancer.

The establishment and success of the peer support and education based survivorship group has resulted in the development of a training manual and the groups becoming a core component of the clinical service delivery for Adolescents & Young Adults (AYA) in Victoria. With the support of the onTrac@PeterMac team, the groups have been adopted in Western Australia by the Adolescent & Young Adult Cancer Service and discussions are currently underway with South Australia and New South Wales for implementation within these jurisdictional areas.

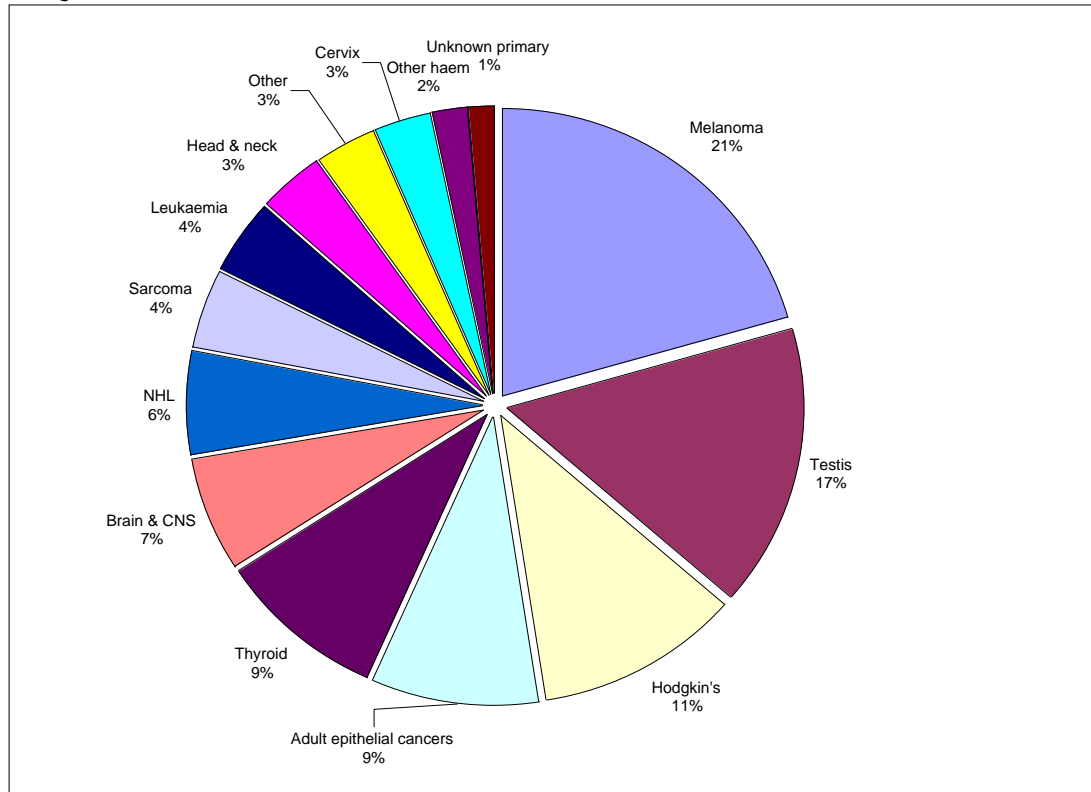
1.2 Burden of cancer amongst the AYA population

Cancer is generally considered to be a disease of the ageing, predominantly affecting the older members of our community. Each year in Victoria roughly 180 children under 15 years are newly diagnosed with cancer with approximately 400 young people between 15 and 30 years and more than 25,000 people over the age of 30. The past 10 years have seen a 30% increase in the number of AYA diagnosed with cancer, with no indication as to why, or whether this upward pattern will continue. Of all the young people diagnosed, approximately a quarter will eventually die from their disease with the mortality rate twice that seen in some paediatric patients with the same diseases. Cancer remains the major cause of non accidental death in the AYA population (Palmer et al. 2008).

The most common cancers affecting this age group are melanoma, lymphoma, germ cell tumours (including testicular cancer), leukaemia, sarcoma (bone and soft tissue), thyroid carcinoma, and colorectal carcinomas (Table 1). These AYA diagnoses represent a unique combination of those seen in the paediatric and adult settings, thus highlighting, the pattern of cancer incidence amongst the AYA as distinctive, requiring a targeted approach to prevention, intervention, treatment and control (Wu et al, 2005).



Table 1. Distribution of cancers in patients aged 15 to 30 years registered to the Cancer Council in Victoria during 2003



Within Victoria, many of the 400 AYA diagnosed with cancer each year will undergo treatment at one or more of the 67 different adult healthcare facilities across the state (Palmer et al 2008). With the geographical spread of these young people, and the impracticality of providing age specific services at each institution, many accessing treatment will experience isolation from peers; will not have access to age appropriate information nor clinicians trained in their unique developmental care requirements.

In response to the unique needs of this group, the Victorian government has committed through the Victorian Cancer Action Plan to strengthen the model of state-wide care for AYA. The establishment of onTrac@PeterMac Victorian Adolescent & Young Adult Cancer Service aims to ensure that every young person living with cancer across the state of Victoria has access to the most current cancer therapies & clinical trials whilst receiving the most comprehensive developmentally targeted psychological, social and emotional support.



1.3 Psychosocial impact of cancer

The Guidelines for Hospital Based Child and Adolescent Care recognise that, within the wider Australian healthcare system, the unique and specific healthcare needs of young people are often unrecognised. The psychosocial needs of the AYA group are specific and differ from those of either children or adults (Smith, 2004; Mulhall et al, 2004; Ritchie, 2001; Society for Adolescent Medicine, 1996; Ellis, 1991).

Due to the developmental changes occurring during the AYA period, the psychosocial challenges faced by young patients are generally broader in scope and intensity than those seen during other life stages (AYAO-PRG, 2006). Compared with children, young people attempting to come to terms with a life threatening illness face the additional challenge of having the cognitive skills to understand the significance of their diagnosis, but unlike adults, they generally haven't developed the coping skills to manage the uncertainty of the diagnosis and its implications (Klopfenstein et al, 2002; Whyte et al, 1997).

In addition to efforts aimed at improving survival, there must be acknowledgement of the need to understand how young people's social and emotional outcomes are affected following a cancer diagnosis with a commitment from the oncology community to develop evidence based interventions aimed to improve long term wellbeing and survival.

1.4 Survivorship issues amongst the AYA population

Recognition is growing within oncology circles both within Australia and overseas that AYA form a distinct group in both acute and post acute service delivery (Thomas et al, 2006, AYAO-PRG, 2006, Palmer et al, 2007, Bleyer et al, 2007, Thompson et al 2009). With the focus of research and care traditionally targeted at the diagnosis and management of malignant conditions, the medical and psychosocial needs of AYA as they transition into the survivorship phase has been comparatively neglected (Soliman et al, 2008, Duffey-Lind et al, 2006).

It is only relatively recently that the numbers of young people completing cancer treatment has increased to such an extent that attention is now being focused on the ongoing needs of those patients who survive (AYAO-PRG, 2006). This is despite the fact that this life stage is arguably



one of the most difficult with the consequences of a cancer diagnosis and treatment affecting a young person's identity, self-esteem, body image, distress levels, peer and family relationships, school and career plans, life perspectives and future prospects for adulthood (Thompson et al, 2009).

The current, yet limited research in the field of AYA survivorship across the world reports the particular importance for young cancer survivors to meet others who have undergone a similar experience. Such opportunities by many young people have been ranked as more important than the support offered by family and friends. (Zebrack et al, 2006, Palmer et al, 2007, Decker, 2007).

2.1 Benefits of cancer support groups

To date much of the research undertaken on the benefit of cancer support and peer interactive groups has been based around the adult population. In a report prepared by The Cancer Council of Australia, titled *Building Effective Cancer Support Groups* (2005), it was demonstrated that support groups have measurable benefits for members including:

- improvements in coping and adaptation
- reductions in general psychological distress
- improvements in levels of depression
- reductions in anxiety
- enhanced self-esteem
- positive effect on immunological response

The report also highlighted the many benefits reported by group participants, such as:

- the opportunity to share experiences and exchange information about cancer and cancer treatments, leading to greater cancer-related knowledge and improved ability to relate to health professionals,
- mutual encouragement and support; empowerment, hope and confidence
- reinforcement of the normalcy of reactions
- increased confidence
- the ability to develop new relationships and socialisation and
- a sense of belonging.



2.2 Support groups for AYA

There is evidence that younger people affected by cancer may suffer higher levels of distress, which might be due to range of issues associated with their developmental stage and/or more limited life experience and problem-solving skills (Thomas et al 2007; Carlson et al, 2004). The use of a psycho-education framework in group work has been identified in the literature as a positive intervention which can enable young people to develop collaborative relationships between themselves and healthcare workers, encouraging active decision making, self regulation and increased self efficacy (Stanton 2005, Corrigan 2002). In addition, in a rare report into peer group support for young people living with cancer, Schwartz (1999) recorded a pre and post test analysis of peer based group support suggesting that participants experienced improved global quality of life (QoL) at the end of treatment. With limited support services for the AYA group across Victoria and the identified unmet needs by Palmer et al (2007) in relation to post treatment follow up and survivorship care, the onTrac@PeterMac team proposed to develop a professionally facilitated peer and education based support group for adolescents and young adults living with cancer.

3.1 Aim

This project aimed to develop a professionally facilitated peer support and education based survivorship group for adolescent and young adults living with cancer in Victoria.

3.2 Objectives

The overall objective of the survivorship group was to build relationships amongst the young people, enhance their coping strategies, support them in acquiring a sense of control and increase their "living with cancer" knowledge base. Ultimately, improving quality of life and assisting them in facilitating a supportive treatment completion period.

In order to achieve this objective, the following indicators were identified as being required:

- development and delivery of age appropriate information and education for young people participating in the support groups



- collaboration with healthcare professionals, onTrac@PeterMac networks and community based agencies in broadly advertising the support groups across metropolitan, regional and rural Victoria
- consumer consultation in the project development, implementation and evaluation to ensure group structure and topics for discussion directly reflect the needs of the AYA population.
- development and delivery of eight facilitated support groups involving a combination of peer support and psycho education
- provision of the opportunity for AYA to meet other young people who have undergone a similar experience
- dissemination of information and outcomes relating to the project both within Victoria and nationally
- consideration of a model of sustainability

This study was submitted approved by the Peter MacCallum Cancer Centre (Peter Mac) Ethics Committee with all participants providing signed, informed consent.

3.3 Literature review

An extensive literature search was undertaken to identify published articles relating to the effectiveness and successful outcomes of support groups for the AYA population. The objective was not a comprehensive literature review, but to identify reviews of the benefits of cancer support groups and the different structures and models available. No Australian reviews relating to the subgroup of AYA living with cancer was found, however papers reporting on the benefits of peer group support in the general AYA population and for some with chronic illness was found. Numerous Australian articles relating to the effectiveness of cancer support groups in the general population were obtained with recommendations for successful group work adopted by the project team throughout the planning and implementation stage of these groups.

3.4 Measuring outcomes

To measure the effectiveness of the group, two questionnaires were chosen as the method of measuring the outcomes in addition to follow up telephone interviews. Illness perception



questionnaires and quality of life questionnaires were completed by all participants prior to their participation in the groups. The Illness Perception Survey, a 56 item self report questionnaire measures how patients think and feel about their illness. A general illness questionnaire, items have been developed to target areas of thinking about one's illness that may impact upon adjustment and healthy behaviours (Moss-Morris et al, 2002). The second questionnaire administered, the SF-36, a quality of life measure, specifically measures one's functional capacity for daily activities, including work and participating in social events, and measures aspects of mood (Ware et al, 2001).

These measures were completed prior to the commencement of the groups and again at the 12 month mark after the initial group had been undertaken to determine if changes resulting from the groups had been maintained by participants. In addition to this a subsequent telephone review was undertaken eight weeks following the completion of all questionnaires.

3.5 Recruitment of Participants:

Participants were invited to join the survivorship group from a clinical data base of AYA patients who had been referred to the onTrac@PeterMac Adolescent & Young Adult Cancer Service and had completed treatment within the previous six month time period. In addition to this recruitment method, there was a targeted approach of the onTrac@PeterMac professional network. This included advertising the group through a range of healthcare providers involved in the management and care of young people throughout metropolitan and regional Victoria.

Over a six week recruitment period, there were there were over twenty five enquiries from young people interested in attending the group. Of the twenty five enquiries, 11 young people attended the groups over the following period. Of the remaining 14 young people, following discussions with the young person and a group facilitator, 7 were referred for individual support from one of the onTrac@PeterMac clinical services including psychiatry, psychology and social work, The remaining young people were deemed to be ineligible for the group as many were outside the post treatment period >2 years. These young people were assessed by the service and where required, a referral was made to an external community agency.

Their cancer diagnosis of those attending the group included: Hodgkin's Lymphoma, Acute Myeloid Leukaemia (AML), Squamous Cell Carcinoma (SCC) Tongue, Metastatic Melanoma, Ewing's



Sarcoma, Osteosarcoma, and Rhabdomyosarcoma. The group had a mean age of 24.9 and 25.8 years of age pre- and post intervention respectively. Three participants were from regional Victoria.

3.6 Group structure:

The support group structure was based on the use of standard group therapy techniques to provide psychological support, establish group cohesion, social interaction, and emphasise the universality of young adult issues (Yalom, 1970). Additionally incorporated into the structure of the groups were psycho educational techniques such as information provision, stress management and problem solving strategies. Groups were held on a monthly basis, after hours at Peter MacCallum Cancer Centre, East Melbourne. Groups lasted for an hour and a half, with a short break in between and a period of socialisation with food and drink at their completion.

Session 1: Welcome

The first group session focused on determining the areas of interest for the members and introducing the structure of the groups. From this session, the following topics were decided:

- a. Living with thoughts of recurrence
- b. Looking back on your experience
- c. Your relationship with your body
- d. Readjusting to life after cancer (Including a guest speaker to discuss your rights in the workplace)
- e. Changes in relationships
- f. Relaxation & meditation (including guest speaker)
- g. Sexuality & Fertility (including a guest speaker)

At the completion of the first session, information packs were provided to each member of the group. In order to facilitate an effective support group for young people, it was essential to provide accurate, reliable, developmentally tailored and up to date information. Accessing Australian information for young people posed a challenge and resulted in the development of handouts by the project coordinator and providing information originating from the United Kingdom and America.



Session 2: Living with thoughts of recurrence

For many young people living with cancer, finishing treatment can be a time of both celebration and despair. Living with the fear of relapse is a major challenge for any cancer survivor, and some have proposed that *'a person never really gets over it'* (Muzzin et al, 1994). Assisting young people to cope through finding a balance between remaining cautious with appropriate monitoring of symptoms and attending surveillance programs with their primary institutions is an important aspect of survivorship support.

This session aimed to encourage participants to discuss their background and experience of a cancer diagnosis and its treatment, allowing them to express their fears with one other, accepting that living with uncertainty would be a normal part of their cancer experience and something they could learn to come to terms with. Through the session, the facilitators worked with the participants to help them to recognise when and how they had lived with uncertainty in other areas of their lives, and how other young people not living with a diagnosis of cancer might also live with uncertainty. Through brainstorming the group supported each other, generating a range of strategies to cope with thoughts and emotions which had continued to present in the months post treatment completion.

"...There's always that niggling fear of recurrence...."

"I constantly feel my breast and under my arm ... constantly"

"... I have this thing where when I get ill now or could be anything where I always relate it back to the cancer. I'm going through a really bad thing at the moment where I'm feeling under my arm for lumps and I'm feeling my body for lumps... it just drives me crazy..."

"...People think that once your cured you should just get back into life....they all return to normal.....you don't..."



Session 3: Looking back on your experience

Due to the complexities of cancer treatment, the often disabling treatment effects, and the rigid timelines, much of the emotional processing associated with a cancer diagnosis does not occur until approaching treatment completion and young people have progressed into the survivorship phase (Palmer et al, 2008). It is often not until this time that the young people regularly start to process the enormity of their experience, the fears associated with surviving a life-threatening illness and the existential issues that may accompany such a life-changing experience.

This session focused on participants reflecting on their experiences, both good and bad.

For many of the participants, this was the first opportunity to discuss a range of issues which were acknowledged by their peers as being of common interest. The main themes to emerge from the session included:

- the recurrent problems of delays in diagnosis; the feeling that there had been undue delay was a common theme for many resulting in considerable resentment towards referring hospitals and medical staff.
- a lack of information provision relating to diagnosis and decision making; the extent of information provision was dependant on the treating institution and varied across the group, although all commented on the lack of high quality Australian information targeted towards the age group.
- treatment environment and the absence of peers within adult institutions; this caused an overwhelming sense of isolation for almost all participants within the group.

There was expressed frustration that healthcare systems have not focused on the simple response of collocating young people together in treatment units. For many this was considered to be cost negative and easy exercise that would significantly improve the treatment experience and psychological outcomes.

Positive experiences were also discussed. This included themes such as changed attitudes about self and life, improved relationships with family and friends, increased capacity for empathy, a desire to help others and deeper feelings for the value of life. Many of the participants spoke of the



bond with members of their treating teams and the subsequent impact that these had had on their lives, particularly in relation to career and vocational choices.

"...There was a lot of information left out.....especially the hard stuff.....after appointments, I'd go home and surf the net.....I'd sit for hours trying to understand what was happening..."

"...The onTrac@PeterMac website was one of the best....it had information about treatment and side effects of chemo. I printed it off and took it to my oncologist....."

"....there were other young people on other ward, yet still I had to share a room with people over 60....why couldn't we be in an area together?..."

".....I'm here.... I survived....my team were fantastic"

Session 4: Your relationship with your body

During the period of adolescence and young adulthood, acceptance of one's physical appearance is a fundamental step towards healthy body image and self-esteem. The physical transformation during this period due to the complex influence of hormones results in a number of changes which can be confusing, confronting and destabilising. The influence of hormones also creates a changing physical environment that is significantly different from that of children or adults who are diagnosed with cancer (Palmer et al, 2008). These physical changes have a profound effect on a young person as they influence their own self-image, how other people respond to them and how their body responds to treatment. For many young people the treatment period has a significant impact on a young person's relationship with their body with some changes short term such as hair loss, weight gain, tumour growth and some that will last forever such as amputations and significant scarring due to surgical procedures.

For some young people, coming to terms with these changes can be difficult. This session focused on a facilitated discussion around these issues with an aim to assist participants to accept changes in their appearance and to broaden their views of the importance of 'looking good'. Through exploring the factors of 'attractiveness' in encompassing personality factors, similar values and ideas between people, participants were encouraged to challenge fears of being 'unattractive' to others due to 'exterior' changes in their bodies. The discussion also explored the sense of 'mistrust of one's body' and the feeling of being 'let down'. Shared experiences and coping



strategies were explored in addition to promoting preventative health and social, physical and psychological wellbeing

"...I definitely think that other things have been affected in my body. I know I'm not the same as I was before. I know I'm tired. I get sick really easily. I know I've been depressed, but no-one talked to me about that..."

"...I had the most gorgeous long hair and I'd always been so vain about my hair and I've been bald most of this year and seeing all your other friends jumping into your room in all the latest outfits and fantastic hair I could sit and talk to them about boring stuff, you know trivial stuff like hair for like half an hour ... what conditioner you're using and stuff like that and suddenly, there you are, with no eye brows and you've gone from looking, you know, glamorous and whatever to being a kind of hairless, horrible creature..."

Session 5: Readjusting to life after cancer (including a guest speaker to discuss rights in the workplace)

The intensity of cancer treatment can have a significant impact on a young person's ability to re-enter education, find or maintain employment. For many young people, following treatment completion, re-entry into the workforce can be impaired by poor self image with regard to their bodies, self identity, self esteem, fatigue, adaptability and attention difficulties. Many young people as a result have concerns in relation to workplace rights, disability support requirements and how, when or if to tell an employer of a previous cancer diagnosis.

This session involved participants sharing the challenges of school, tertiary and employment reintegration following cancer treatment and care. A list of common concerns and questions were generated for the second half of the session which a guest speaker attended. Themes of the discussion focused around: i) preparing for returning to work; ii) assisting in the process of finding the right type of employment; iii) applying for and successfully obtaining employment, iv) moving into and being supported in employment and v) rights and entitlements.

"...I got totally lost after I had cancer. I was told I couldn't do my job anymore, so I was just trying to think of what I was going to do with my life..."



"...Do you tell your new employer....hey by the way, I have an appointment at Peter Mac next Tuesday....can I have the morning off?..."

"...I know that a former employer that I've had, if I had been working there and I had cancer he would have said well I need someone else who's going to be here and he would have forced me to resign. So at the end of the day it's the luck of the draw who your employer is ... and how they are to help you out..."

Session 6: Changes in relationships

Relationships are strongly influenced during the developmental period of adolescence and young adulthood. As a young person works towards independence from their parents and other adult authority figures, they are building new and meaningful relationships with others of the same and opposite sex. However, for many this can change following a cancer diagnosis.

This session focused on the broad range of relationships within participant's lives and how these have been both positively and negatively influenced by a cancer diagnosis. Most of the participants agreed that their families played a significant role during the treatment period and many spoke of the challenge of the reliance on family having only just achieved partial independence and separation from parents. By the same token, many discussed the process of separation after treatment as posing a challenge with the new attachments that had been formed. Changes in relationships with peers were also explored. Some discussed the challenge of feeling 'left behind' and 'forgotten' as peers developed new friendships around them often associated with new educational and vocational opportunities. However, for most participants, by far the greatest relationship change was associated with the current or development of intimate relationships.

For many of the young people having completed treatment, residual effects of treatment such as alopecia, weight gain, fatigue, limb loss all impacted one's body image and confidence in intimate and sexual relationships with partners. For those who were seeking new relationships the daunting notion of when to disclose to a potential partner having had a cancer diagnosis was significant.

This session generated great discussion of the multiple experiences and stories participants had experienced over the months since treatments completed. The experience of the facilitators in sexual counselling provided an opportunity for broad discussion in relation to the physical and emotional sexual health wellbeing. Strategies and techniques were shared amongst participants and the level of confidence within the room was palpable.



"...It's hard for me because ... I want to be my own person and my parents want to give me money but I want to do it all on my own and ... it's hard being accepting that way..."

"...I don't like telling people that I have cancer because they just get sad..."

Session 7: Fertility & Sexuality (including a guest speaker)

There was a two month break between this and the previous session due to complications with the guest speaker.

Young people living with cancer are confronted with sexual and reproductive issues at diagnosis, during treatment and as long term survivors. Issues surrounding fertility and sexual functioning are important with each young person requiring specific information relating to ongoing contraception options, treatment related libido and functioning problems.

Fortunately there is an increased awareness amongst treatment teams of the need to talk to young people about fertility preservation before they commence treatment. However for many young people having to consider their future fertility on the background of a cancer diagnosis and the planning of treatment can be extremely stressful and traumatic. Many report feeling rushed, as invasive investigations are undertaken, multiple specialist appointments are attended, and treatment was organized whilst they were still just starting to terms with their diagnosis. For some having a child was reported to being something they had never considered and the last thing they wanted to think about at such a time.

During this session, many of the participants reported not retaining information provided in relation to the long term impact of treatment on fertility preservation following their cancer diagnosis. Most had never really had the opportunity to discuss in further detail the subsequent questions which arose. Detailed discussions were undertaken regarding the options for fertility preservation for males which is far more straightforward to that of females. Rational for routine fertility reviews post treatment were discussed as well as options for those amongst the group who did not have the opportunity to consult with a fertility specialist prior to the commencement of therapy. There were also discussions relating to the impact of sexual functioning, in particular issues such as decreased libido, the inability to achieve or maintain sexual arousal and the delay or absence of orgasms.



"... You know, on top of everything else ... it is so hard to deal with the fact that you may never have children..."

"...I think being a female it was harder again with age specific differences regarding fertility and what type of treatment you were going to have. A lot of the specifics about if you have this done, after chemotherapy you have a 50% chance, but none of the specifics were for 25 year olds with cancer. They were all for, you know, the people they had done research on, who were over 50. And their reproductive systems and fertility at that age is much different from at 25 and how do you make those decisions?..."

"I felt fatigued, I really just felt fatigued and in terms of intimacy, it definitely changes everything ... you don't feel the same ... you don't have the same wants as you did previous to, you know, starting chemo. I'm just starting to get back into things sexually now..."

Session 8: Relaxation, meditation, and finishing the group

This session was the final one in the planned eight session series. The focus was a discussion on stress management and techniques and strategies which could be adopted by participants in times of heightened anxiety. Many of the participants stated utilising complimentary therapies at some stage throughout their treatment, yet felt there was a lack of acceptance by their treating teams as to its benefits or usefulness. Many reported doing so assisted them in coping with their situation and improved overall mood.

This session saw the facilitator provided a guided imagery session assisting participants to find a relaxed focus state. A number of handouts and relaxation CDs were provided to each group member to take away with them.

A focus of the final half hour was closing the group and allowing the participants to say their farewells. For many of the participants the last session of such a group can signify the end of an experience that has meant a lot to them. Over the last nine months there had been many different experiences and participants had been exposed to a range of new information and ideas. Many of the participants had trusted all in attendance and had explored sensitive and emotional issues for the first time.



Each participant including the facilitators were encouraged to share what they had personally/professionally got out of the group and one of the most important things they would take away with them.

"...I don't identify my self as a cancer patient anymore.....I'm 22 and just happened to have had a cancer diagnosis..."

3.7 Results:

Questionnaire data

Of the eleven young people who attended the support group and completed the pre-intervention questionnaires, nine (8 female, 1 male) completed the post-intervention measures at 12 months (82%). Only participants who completed both sets of questionnaires were included in the analyses.

The IPQ-R is a self-report questionnaire that measures a patient's cognitive model of their illness in five dimensions: identity (i.e. the related symptoms), cause, timeline (i.e. a short-term or lifelong illness), consequences and cure/controllability of the illness. The SF-36 is a quality of life measure that specifically measures one's functional capacity for daily activities, including work and participating in social events, and measures aspects of mood.

In the statistical analyses, t-tests were performed to compare differences in pre- and post-intervention scores on the two questionnaires. Results showed that there was no statistical difference between pre- and post-intervention responses on the IPQ-R. On the SF-36, problems with work or other daily activities reported were significantly lower after the intervention compared to pre-intervention scores. No other differences were found over the 12-month period.

In addition to the questionnaires, participants were asked to specify their survivorship issue/s and their reason for attending the group pre- and post-intervention. Six of the nine participants reported that they attended the group to meet others with cancer or similar experiences prior to the intervention, one of which specified the need to meet others of a similar age. After the intervention, however, all nine participants reported that they attended the group to meet and talk to others with similar experiences, and five emphasised the need to share with others of a similar age. The only



other prominent theme was the transition to life after cancer, for which three participants reported as their reason for attending prior to the intervention, but only one reported this post-intervention. Although more investigation is needed, particularly among males, as there was only one male participant who completed the questionnaires, this is a clear indication of the desire for peer support among young people with cancer.

Of the survivorship issues there was no single issue that stood out prior to the intervention. Practical issues such as career and financial concerns were reported by four of nine participants both pre- and post-intervention, but by the older group members aged between 24 and 31 years old. Although fear of relapse was only reported by two participants prior to the intervention, it was the most prevalent survivorship issue post-intervention, reported by seven of the nine participants. The remaining survivorship issues were fertility, relationships (including friends and family), mental health and body image and physical re-adjustment to life after cancer. These issues were all listed by four participants pre- and post-intervention.

The statistical findings of this study provided inconclusive evidence of the effectiveness of peer and psycho educational group intervention for young people following cancer treatment.

Telephone Interview

Eight weeks following the completion of the questionnaires, follow up telephone contact was attempted with each participant, of which 10 were successful. The follow up call aimed to receive reflective feed back on the group experience and to see whether participants had continued to experience positive interventions as a result of the both the peer connection and psycho-educational support. Questions asked of participants included:

- How relevant was the support group in relation to your experience as a cancer survivor?
- What was your most positive experience attending the survivorship group?
- What positive benefits have you noticed from your participation in the survivorship group?
- What valuable skills did you learn that you feel will impact your overall wellbeing?
- How do you think we could improve the survivorship group in the future?

Whilst there were specified questions, discussions evolved by telephone with each participant. Common themes were identified during the discussions as grouped below, with a selection of accompanying comments.



Relevance of a survivorship support group for Adolescents & Young Adults:

All participants spoke of the need for structured post treatment support both within the physical and psychosocial domain. The period of survivorship for many was deemed to have induced higher levels of anxiety than both the time of diagnosis and whilst undergoing active therapy. Many spoke of the group providing the only forum other than infrequent medical follow up appointments as being the only opportunity to share experiences with others and seek emotional support. A small number of participants spoke of seeking community based survivorship services prior to the group through non government agencies and general practitioners. No services were found to be available specifically associated with the area of cancer survivorship, with late effects issues not well understood by general practitioners. One participant commented that while the group was beneficial, it should be seen as 'part of' the survivorship package which needs to be developed.

Opportunity to meet other young people:

Most participants highlighted having met other young people through the groups as being one of the most positive outcomes. They reiterated that the opportunity to discuss their experience with people of a similar age had normalised thought processes and experiences. Commonly expressed by participants was appreciation towards other group members in relation to the sharing of information, coping strategies and practical suggestions on topics of concern.

Some of the participants reported they had maintained contact with other group members on a social level following the completion of the group.

"....It was great to meet other young people....reassuring that I wasn't alone in my thoughts...."

".....I have kept in contact with a couple of others from the group.....we catch up for coffee regularly...."

Opportunity to speak with healthcare professionals and specialists through guest presentations:

Many of the young people in the follow up phone conversations spoke of the benefits of having access to healthcare professionals experienced in the management of young people living with



cancer. For some, they had limited access to supportive care staff throughout treatment and relied heavily on ward based nursing staff. Participants also reported the benefits of having access to guest speakers and adequate time to seek information, clarify advice and follow up with individual appointments if required. One participant had accessed recommended employment support and had successfully gained part time employment for the first time in eighteen months. Another participant spoke of subsequently seeing a fertility specialist.

"...I was able to talk about what happened with others who truly understood.....it was also great to have Kate & Susan who were able to help me see things differently..."

Opportunity to implement skills developed and psycho educational techniques learnt:

All of the participants in the group spoke of utilising the information and education received post group completion. For some this related to discussing with treatment teams plans for ongoing follow up and for others it related to making appointments with specialists to discuss further issues raised within the group. A number of the young people spoke of adopting some of the psycho educational strategies including cognitive behavioural techniques (CBT), relaxation and meditation techniques. Other participants spoke of adopting a number of suggestions provided in the session handouts.

"...Every time I used to think about my cancer, my heart would race and I would have difficulty catching my breath.....the relaxation strategies and deep breathing has really helped....."

"...My partner and I made an appointment straight after the fertility session; it really gave us hope that we could still have children..."

.....I haven't had such great sex in over a year, the ideas shared by the group work!...."

Suggestions for further improvements:

There were a range of suggestions by participants in relation to possible improvements to the survivorship group. These included twice monthly groups rather than monthly, facilitating groups outside the hospital environment and access to an oncologist/haematologist as an additional guest speaker. Many spoke of the need to improve overall survivorship services for people having had a cancer experience and that it should be seen as a component within an overall package for young



people post treatment. One participant spoke of the need for a post treatment group for partners, acknowledging the impact a cancer diagnosis has on intimate relationships during this life stage and another spoke of the need for a parent group. These suggestions alone highlight the complexities in the relationships and roles of people in the lives of young people at this age and the need for a family centred model of support whilst at the same time as balancing the autonomy, development and needs of the young person.

3.8 Study Limitations:

There were multiple limitations in this pilot study when reporting on the statistical results obtained. The choices of questionnaires given the small sample size are unlikely to have detected statistically significant differences between pre and post intervention scores, nor effectiveness of the group as they were unable to reflect the content covered and psycho education provided. On reflection, the success of the intervention would have been more appropriately measured by global scales such as an 'Overall Satisfaction Scale' or 'Global Improvement Scale'. These measures have been recommended for the subsequent groups both within Victoria and across other jurisdictions.

The qualitative results, however clearly reflect positive outcomes experienced by young people as far as the post group follow up phone interview. However, whilst there was an attempt to structure these interviews they resulted in being often directed by the young person in a narrative framework thus being a challenge to analyse any other outcome than common and general themes.

Other challenges impacting on the overall project included the high turn over of staff on both the project team and on the steering committee. Whilst replacements were often found within the healthcare field, consistency and a clear understanding of the over all project aims by all members required intensive time allocation from project leaders. Replacements from community representatives were not made due to externally influencing circumstances.

The challenge of recruiting guest speakers who are often specialists in their fields posed a limitation when there were cancellations and the need to reschedule groups which resulted in logistical difficulties contacting members, rescheduling catering and room availability. In addition, not having back up facilitators trained in adolescent & young adult development placed an additional pressure when illness or absences occurred.



The final challenge is the support of young people wishing to access such support from rural and regional areas. Due to the disbursement of young people across the health system and the diluted numbers in regional areas young people are often required to travel distances, resulting in a significant time & financial impact. Whilst the participants in this project received financial support from onTrac@PeterMac for travel and accommodation costs, funding opportunities would have to be explored for long term sustainability.

3.9 Conclusion:

“Cancer survivorship” is a term that has come to represent the state or process of living following a diagnosis of cancer, regardless of how long a person lives. It is a concept used by many health care professionals, researchers, and cancer patients to understand not only the physical but also the social, psychological, and spiritual/existential impact of cancer on one’s life and for the remainder of one’s life (Zebrack, et al 2006).

Due to the complexities inherent in the AYA stage of life, it can be argued that a diagnosis of cancer and its management in the post treatment period can result in more long term negative consequences than for adults or children (Mulhall et al., 2004; Ritchie, 2001; Ellis, 1991).

However, cancer and the issues of survivorship during the teenage and early adult years remains amongst the most under researched areas in oncology. Assumptions regarding the appropriate management and support of AYA patients from diagnosis, through active therapy and into the survivorship period are largely based on studies conducted with other age groups and are not appropriately targeted towards the specific needs of the AYA population.

This study aimed to explore the benefits of a facilitated peer support and education based survivorship group for AYA in the post treatment period. Support groups across the oncology field and within adolescent health are an identified intervention based on sound theory and empirically supported treatment models, supporting the hypothesis of benefit for the AYA cohort.

Within this study however, results were inconclusive in findings, with practice implications overlapping with the research implications. The possibility that peer and psycho educational group treatments work for supporting young people following a cancer diagnosis remains a viable hypothesis, and as such should not be abandoned. However, given the findings do not suggest



that the treatments provided through the group had a large impact on levels of psychosocial functioning; healthcare professionals should consider using this treatment in conjunction with other models of intervention and referral when working with young people until further larger studies utilising both qualitative and quantitative methods can support its efficacy.

3.10 References:

Bleyer, A., Barr, R., (2007) *Cancer in Adolescents & Young Adults*, Springer-Verlag, Berlin.

Cancer Council Australia., *Building Effective Cancer Support Groups: Report to the Department of Health & Ageing* (2005)

Carlson LE, Angen M, Cullum J, Goodey E et al. (2004) *High levels of untreated distress and fatigue in cancer patients*. Br J Cancer, 90(12), 2297-304.

Decker, C., (2007) *Social support and adolescent cancer survivors: A review of the literature*. Psycho-oncology, 16, 1-11.

Duffy-Lind, E., O'Holleran, E., Healey, M., Vettese, M., Diller, L. & Park, E., (2006) *Transitioning to Survivorship: A Pilot Study*. Journal of Paediatric Oncology Nursing, 23(6) 335-343

Ellis, J., *Coping with adolescent cancer: It's a matter of adaption*. Journal of Pediatric Oncology Nursing, 8(1), 10–17. (1991)

Klopfenstein, K. & Young-Saleme, T., *Your role in the spectrum of adolescent cancer: Diagnosis through treatment to care at life's end*. Contemporary Pediatrics, 19(8), 105–127. (2002).

Moss-Morris, R., Weinman, J., Petrie, K., Horne, R., Cameron, L. & Buick, D. (2002) The Revised Illness Perception Questionnaire (IPQW-R) Psychology & Health, 17 (1) 1-16.

Mulhall, A., Kelly, D. & Pearce, S., A qualitative evaluation of an adolescent cancer unit. *European Journal of Cancer Care*, 13, 16–22. (2004)

Palmer, S., & Thomas, D., (2008) A Practice Framework for working with 15-25 year old cancer patients receiving care in the adult health sector, *Unpublished*.

Palmer, S., Mitchell, A., Thompson, K. & Sexton, M (2007). *Unmet needs among adolescent cancer patients: a pilot study*. Palliative and Supportive Care, 5(2), 127-134.

Report of the Adolescent and Young Adult Oncology Progress Review Group (AYAO-PRG), (2006) *Closing the Gap: Research and Care Imperatives for Adolescents and Young Adults with Cancer*. US Department of Health and Human Services.



Ritchie, M., *Psychosocial nursing care for adolescents with cancer*. *Issues in Comprehensive Pediatric Nursing*, 24, 165–175. (2001)

Schwartz CE (1999) *Teaching coping skills enhances quality of life more than peer support: results of a randomized trial with multiple sclerosis patients*. *Health Psychology*, May;18:211–20.

Smith, S., *Adolescent units – An evidence based approach to quality nursing in adolescent care*. *European Journal of Oncology Nursing*, 8, 20–29. (2004)

Society of Adolescent Medicine, *Adolescent inpatient units: A position statement of the society for adolescent medicine*. *Journal of Adolescent Health*, 18, 307–308. (1996)

Soliman, H. & Agresta, S., (2008) *Current Issues in Adolescent & Young Adult Survivorship*. *Cancer Control*, 15(1) 55-62

The Cancer Council Australia (2005) *Building Effective Cancer Support Groups*

Thomas, D., Seymour, J., O'Brien, T., Sawyer, S. & Ashley, D., (2006) *Adolescent and young adult cancer: a revolution in evolution?* *Internal Medicine Journal*, 36, 302-307.

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*, doi:10.1016/j.ejon.2009.05.001

Ware, J. & Kosinski, M. (2001) *SF-36 Physical & mental health Summary Scales: A Manual for Users of Version 1. Second Edition*. Lincoln, RI: QualityMetric Incorporated

Whyte, F. & Smith, L., *A literature review of adolescence and cancer*. *European Journal of Cancer Care*, 6, 137–146. (1997)

Wu, X., Groves, F., McLaughlin, C., Jemal, A., Martin, J. & Chen, V., *Cancer incidence patterns among adolescents and young adults in the United States*. *Cancer Causes and Control*, 16, 309–320. (2005)

Zebrack, B., Bleyer, A., Albritten, 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.