



NOVA

University of Newcastle Research Online

nova.newcastle.edu.au

Hall, Alix Edna, Boyes, Allison Wendy, Bowman, Jennifer, Walsh, Raoul A., James, Erica L., Girgis, Afaf, "Young adult cancer survivors' psychosocial well-being: a cross-sectional study assessing quality of life, unmet needs, and health behaviors". Originally published in Supportive Care in Cancer Vol. 20, Issue 6, p. 1333-1341 (2012).

Available from: <http://dx.doi.org/10.1007/s00520-011-1221-x>

The final publication is available at [www.springerlink.com](http://www.springerlink.com)

**Accessed from:** <http://hdl.handle.net/1959.13/1038617>

**This is the author-created version of this article. The authors would like to acknowledge that the final article is published by Supportive Care in Cancer and can be accessed at the following link:**

<http://www.springerlink.com/openurl.asp?genre=article&id=doi:10.1007/s00520-011-1221-x> **The final publication is available at [www.springerlink.com](http://www.springerlink.com)**

**Young adult cancer survivors' psychosocial well-being: A cross-sectional study assessing  
Quality of Life, unmet needs and health behaviors**

(Running title: **Young adult cancer survivors' psychosocial well-being**)

Alix E. Hall<sup>1</sup>, Allison W. Boyes<sup>1</sup>, Jennifer Bowman<sup>2</sup>, Raoul A. Walsh<sup>1</sup>, Erica L James<sup>3</sup>, Afaf  
Girgis<sup>4</sup>

<sup>1</sup> Centre for Health Research & Psycho-oncology (CHeRP)

Hunter Medical Research Institute & Priority Research Centre for Health Behaviour,  
University of Newcastle  
Newcastle, Australia

<sup>2</sup> School of Psychology, Hunter Medical Research Institute, Priority Research Centre for  
Health Behaviour & Priority Research Centre for Brain and Mental Health

University of Newcastle  
Newcastle, Australia

3. School of Medicine and Public Health, Hunter Medical Research Institute, Priority Research  
Centre for Health Behaviour & Priority Research Centre for Physical Activity and Nutrition,

University of Newcastle  
Newcastle, Australia

4. Centre for Health Research & Psycho-oncology (CHeRP), Hunter Medical Research Institute  
& Priority Research Centre for Health Behaviour, Cancer Council NSW and University of

Newcastle  
Newcastle, Australia

**Correspondence**

Alix Hall

Centre for Health Research & Psycho-oncology

Room 230A, Level 2, David Maddison Building

University of Newcastle

Callaghan NSW 2308 Australia

[alix.hall@newcastle.edu.au](mailto:alix.hall@newcastle.edu.au)

+61 2 4913 8601 (fax); +61 2 4913 8604 (telephone)

## **ABSTRACT**

**Purpose:** This study compared the unmet needs, quality of life (QoL) and health behaviors (smoking, alcohol, physical activity) of young adult cancer survivors to their older counterparts and age-related peers.

**Methods:** We conducted a subset analysis of the *Cancer Survival Study* baseline data collected from participants surveyed at approximately 6-7 months post diagnosis. All 58 young adults aged 18-40 years at the time of first primary cancer diagnosis and participating in the study were included. Their responses to the self-administered SCNS-SF34, EORTC QLQ-C30 and standard items assessing smoking, alcohol consumption and physical activity were compared to a random sample (n=58) of gender and cancer-type matched older adults (64+ years) participating in the same study. Young adult survivors' health behaviors were also compared to previously published data for age-related peers from the Australian general population.

**Results:** Young adult cancer survivors reported significantly lower levels of social functioning; higher levels of financial difficulties, sexuality needs, health systems and information needs, and better physical functioning than their older counterparts. A significantly higher percentage of young cancer survivors were current smokers compared to older survivors (16.1% vs. 3.7%,  $p=0.03$ ), but is lower than that reported by age-related peers (24.8%). Compared to young cancer survivors (27.3%) significantly fewer older cancer

survivors (8.3%,  $p=0.046$ ) and more age-related peers (53.6%) engaged in sufficient levels of physical activity.

**Conclusions:** The impact of cancer on young adults seems to be specific. Future research should verify the unique concerns of young adult cancer survivors in large and diverse samples.

**KEYWORDS:** cancer survivors, health behaviors, psychosocial oncology, quality of life, young adulthood

## INTRODUCTION

The incidence of some cancers (eg. tongue, colorectal) is increasing amongst young adults worldwide [1-3]. For example in 2005, 5% of all new cancer diagnoses (excluding non-melanocytic skin cancer) in Australia were in young adults aged 20 to 39 years, representing a 4% increase from 1995 [4]. This population is important because past research has consistently identified younger age at diagnosis as associated with increased risk of psychosocial problems. Some studies have found that compared to older adults with cancer, young adults report poorer global quality of life (QoL) [5]; higher levels of depression [5-7], anxiety [6-7] and poorer body image [8]. Socially, young adults have reported greater disruptions in life [9] and more financial concerns related to cancer [7]. Some research also suggests the physical effects of cancer may be greater for young adults, with reports of worse sexual functioning [10] and higher levels of bodily pain [8].

The health behaviors of those with cancer is pertinent because smoking abstinence, low alcohol consumption and sufficient exercise are associated with reductions in some long-term side-effects from treatment, increased levels of QoL [11-13], and potentially lowers the risk of: cancer recurrence; a second primary cancer; chronic diseases and mortality [12, 14]. Of all age groups, young adults in Australia have the highest rates of smoking (19% to 28%) [15] and consuming alcohol at risky levels at least once a week (14%) [16]. Two studies which analyzed large population-based data found that compared to their cancer-free peers, young adult cancer survivors were more likely to be current smokers [17, 18]. It is vital that healthy lifestyle behaviors are encouraged amongst young adults with cancer given that some behaviors (eg. physical activity) have been shown to decline with increasing age [19].

Although knowledge about the experiences of young adult cancer survivors is emerging, there are still many gaps. Much research conducted to date has focused on those with breast cancer [10, 20-21] despite the diversity of cancer types that young adults are diagnosed with. Few studies have focused specifically on young adults and have instead grouped them with samples of middle aged or older cancer patients [9, 20]. Furthermore, little research in this area has been conducted in Australia; given that cancer is not experienced uniformly across the world, the application of the existing evidence to the Australian context may be limited.

Identifying the psychosocial issues and health behaviors that are unique to young adult cancer survivors will enable us to offer tailored support services and models of care. This study aimed to (i) compare the unmet needs, QoL and health behaviors of a diverse sample of young (18-40 years) Australian adult cancer survivors to older ( $\geq 64$  years) adult cancer survivors matched for gender and cancer type and (ii) compare the health behaviors of young adult cancer survivors to similarly aged peers from the Australian general population. Our definition of young adults (18-40 years) was based on that used by the National Cancer Institute [22].

It was hypothesized that young adult cancer survivors would: (i) report lower levels of QoL and higher levels of unmet needs compared to older adult cancer survivors; (ii) report higher rates of smoking and alcohol consumption compared to both older adult cancer survivors and their age-related peers; (iii) be more active than older adult cancer survivors but less active than age-related peers.

## **METHOD**

### **Participants and procedures**

This study was a subset analysis of the *Cancer Survival Study*, a population-based longitudinal study investigating the physical, emotional and psychosocial well-being of a cohort of 1,453 cancer survivors over the first five years since diagnosis [23]. The current study analyzed data collected from participants approximately 6-7 months post diagnosis (Time 1). Two sub-samples were drawn: all young adults aged between 18 and 40 years at time of diagnosis (n=58) and 58 randomly selected older adults aged 64 years and over, matched for gender and cancer type.

Participants were recruited from the two largest cancer registries in Australia. Patients aged 18 to 80 years at time of diagnosis with their first primary cancer (localized or metastatic) of one of the top eight incident cancers in Australia (prostate, breast, bowel, melanoma, lung, non-Hodgkin's lymphoma, leukemia, head and neck); regarded by the primary physician to be fluent in English, aware of their diagnosis, and mentally and physically capable of participating, were eligible. Eligible patients were approached by the Cancer Registry requesting consent to provide their contact details to the researchers. Consenting survivors were sent a self-report pen and paper survey and reply-paid envelope. Non-responders were sent a reminder package after 3 weeks and contacted by telephone after a further 3 weeks. Return of the survey was taken as consent to participate. The study was approved by the University of Newcastle Human Research Ethics Committee.

The following sub-sets of previously published data for the Australian general population were also used:

*Smoking and alcohol* data from 30-39 year olds who participated in the 2007 Australian National Drug Strategy Household Survey [24]. These data were collected via a drop and

collect survey and a Computer Assisted Telephone Interview (CATI) of randomly selected households. Of 23,356 people who took part in the survey, 18% were aged between 30 and 39 years [24].

*Physical activity* data from adults aged 35-44 years who participated in the 2008 New South Wales Population Health Survey [25]. Participants were randomly selected by random digit dialing of household numbers. The CATI was completed by 12,485 people of which 10.1% were aged between 35 and 44 years [25].

## **Measures**

*Patient details:* Age, sex, cancer type and spread of disease were obtained directly from the Cancer Registries. Marital status, education, health insurance, income, employment, treatments received and co-morbidities were obtained through a standardized self-report survey.

*Quality of Life (QoL):* European Organization for Research and Treatment of Cancer Quality of Life Questionnaire – version 3 (EORTC QLQ-C30) is a 30-item measure of QoL consisting of five multi-item functional scales (physical, role, emotional, cognitive, social); three multi-item symptom scales (fatigue, pain, nausea/vomiting); six single-item symptom scales (dyspnoea, insomnia, appetite loss, constipation, diarrhea, financial difficulties); and one multi-item global QoL scale [26]. Scale scores range from 0 to 100. A high score on a functional or global QoL scale represents a high level of functioning [27]. A high score on a symptom scale represents a high level of problem [27].

*Unmet needs:* Supportive Care Needs Survey – Short Form (SCNS-SF34) is a 34 item measure of perceived need. There are five domains: psychological (10 items), health systems and information (11 items), patient care and support (5 items), physical and daily living (5

items), and sexuality (3 items) [28]. Domain scores can be standardized to range from 0 to 100 with a high score indicating a high level of perceived need, or raw domain scores can be dichotomized into ‘some need’ vs. ‘no need’ [29].

*Smoking:* Two questions assessed participants’ smoking behavior. Participants were classified as current, (daily, weekly, less than weekly), ex- or never smoker [30].

*Alcohol consumption:* Two questions adapted from the Australian National Drug Strategy Household Survey [31] assessed participants’ alcohol consumption and frequency. Consuming more than two standard drinks on any day was classified as being at increased lifetime risk of harm from alcohol related injury or disease, based on the most recent guidelines [32]. Older guidelines [33] classified weekly consumption as abstainers (no drinks), low risk (up to 28 drinks for males and up to 14 for women), risky (29 to 42 for men and 15 to 28 for women) or high risk drinkers (43 or more for men and 29 or more for women). The older guidelines [33] were used in conjunction with the most current guidelines [32] to enable comparisons with population-based data. ‘Binge drinking’ was defined as consuming 5 or more drinks on any one day, consistent with previous research [34].

*Physical Activity:* Three items adapted from the Active Australia survey [35] assessed frequency and time engaged in mild (e.g. easy walking); moderate (gentle swimming); and vigorous (jogging) physical activity during the past week. Participants were classified as ‘sufficiently active’ (at least 150 minutes of moderate-vigorous physical activity across five or more sessions per week), ‘insufficiently active’ or ‘sedentary’ [35].

## Statistical analysis

Missing items were imputed for the QLQ-C30 and SCNS-SF34 according to recommendations [27, 29]. Raw scores were calculated for each scale of the QLQ-C30, transformed to standardized scores ranging from 0 to 100, and descriptive statistics calculated. To examine the differences between young and older adults' mean QoL scores, commonly used mean score change criteria were used to identify small (5-10 points), moderate (10-20 points) and large ( $\geq 20$  points) clinically important differences [36]. Clinical significance is recognized as an appropriate method for assessing differences in QoL scores as it provides an indication as to whether the difference is large enough to have patient management implications [37]. Young and older adults' unmet needs and engagement in health behaviors were compared using Chi-squared ( $\chi^2$ ) or the Fisher's Exact test ( $p \leq 0.05$ ). The prevalence of health behaviors among young adults with cancer compared to aged-related peers from the Australian general population [24, 25], were not tested for statistical significance due to differing methodologies and age groups. Due to the small number aged 18-29 years ( $n=9$ ), it was not appropriate to further segregate the sample of young adult cancer survivors to more closely match the age groupings used in the general population data.

## RESULTS

### *Participants*

Of the 1,691 potential participants who agreed to be contacted about the *Cancer Survival Study* by the researchers, 1,360 returned a completed Time 1 survey. The analyses reported in this paper included data from all 58 young adults who returned a completed survey as well as 58 matched older adults. The mean age at diagnosis was 35 years ( $SD = 4.8$  years) for young adults and 70 years ( $SD = 4.3$  years) for older adults. Mean time since diagnosis was 7

months (SD = 1.29). The demographic and clinical characteristics of the two groups are summarized in Table 1. Compared to older adults, a significantly higher percentage of young adults were university or technical college educated ( $\chi^2=10.0$ ;  $df=1$ ;  $p<0.001$ ), had a weekly gross family income of \$500 or more ( $\chi^2=27.6$ ;  $df=1$ ;  $p<0.001$ ) and were currently employed ( $\chi^2=33.9$ ;  $df=1$ ;  $p<0.001$ ).

INSERT TABLE 1 HERE

### *Quality of life*

Although QoL was similar for both age groups across most domains, some clinically significant differences were identified. As shown in Table 2, young adults reported slightly better physical functioning and slightly fewer problems from constipation than older adults. However, young adults reported slightly worse social functioning and moderately higher levels of financial difficulties compared to older adults. There were no clinically significant differences between young and older adults' scores for global QoL; role, emotional and cognitive functioning; and fatigue, nausea, pain, insomnia, appetite loss and diarrhea symptom scales.

INSERT TABLE 2 HERE

### *Unmet Needs*

A statistically significantly higher percentage of young adults reported 'some need' for help with health system & information needs (44.8%; [95%CI: 31.8%, 57.8%] vs. 23.6%; [95%CI: 12.2%, 35.0%]) ( $\chi^2=5.6$ ;  $df=1$ ;  $p=0.02$ ) and sexuality needs (29.3%; [95%CI: 17.4%, 41.2%] vs. 10.7%; [95%CI: 2.5%, 18.9%]) ( $\chi^2=6.1$ ;  $df=1$ ;  $p=0.01$ ) compared to older adults. There were no significant differences in the percentage of young and older adults reporting 'some need' for help with psychological (46.6% [95%CI: 33.5%, 59.6%] vs. 50% [95%CI: 36.5%, 63.5%]), physical & daily living (36.2% [95%CI: 23.6%, 48.8%] vs. 35.2% [95%CI: 22.2%,

48.1%]), and patient care & support (19.0% [95%CI: 8.7%, 29.2%] vs. 21.8% [95%CI: 10.7%, 32.9%]) needs.

Table 3 shows the top five moderate/high needs reported by young adult cancer survivors, and the corresponding percentage of older adults who reported a moderate/high need for help with each of those items. Of the top five needs, five related to the psychological domain and one to the physical and daily living domain. Although a higher percentage of young adults indicated a moderate/high need for help on each of the top five items compared to their older counterparts, this difference was statistically significant only for ‘uncertainty about the future’.

INSERT TABLE 3 HERE

### *Smoking*

Approximately half of young (55.4%) and older adult (51.9%) cancer survivors reported having never smoked. A further 42.6% of older and 26.8% of young adults reported having quit smoking. A significantly higher percentage of young (16.1% [95%CI: 6.3%, 25.8%]) compared to older adults (3.7% [95%CI: 0.0%, 8.8%]) ( $\chi^2=4.7$ ;  $df=1$ ;  $p=0.03$ ) were current smokers.

As shown in Figure 1, a lower percentage of young adults with cancer reported being a current smoker compared to a group of young adults (30-39 years) from the Australian general population.

INSERT FIGURE 1 HERE

### *Alcohol consumption*

Approximately 24.1% of young and 35.1% of older adult cancer survivors reported never having had a serve of alcohol. Of those who had consumed at least one serve of alcohol, no

significant differences were identified in the percentage of young (29.3% [95%CI: 17.4%, 41.2%]) and older (14.3% [95%CI: 5.0%, 23.6%]) adults who reported consuming alcohol at a rate that placed them at increased risk from lifetime harm due to alcohol related injury or disease; nor in the percentages of young (13.8% [95%CI: 4.8%, 22.8%]) and older (3.6% [95%CI: 0.0%, 8.5%]) adult cancer survivors who reported binge drinking on at least one occasion over the last six months.

As shown in Figure 2, a similar percentage of young and older cancer survivors were classified as consuming alcohol at a risky/high level. Compared to similarly aged peers (30-39 years), a lower percentage of young adult cancer survivors were classified as consuming alcohol at a risky/high level.

INSERT FIGURE 2 HERE

#### *Physical activity*

As shown in Figure 3, a significantly higher percentage of young adult cancer survivors (27.3% [95%CI: 15.3%, 39.2%]) were engaged in sufficient levels of physical activity compared to older adults (8.3% [95%CI: 0.4%, 16.3%]) (Fisher's exact,  $p=0.046$ ). A lower percentage of younger adult cancer survivors engaged in sufficient levels of physical activity (27.3%) compared to a similar aged (35-44 years) cohort from the NSW general population (53.6%).

INSERT FIGURE 3 HERE

## **DISCUSSION**

Despite previous research suggesting that young adult cancer survivors fare considerably worse than their older counterparts across multiple domains of life, our study suggests that

young adults may not be performing as poorly as previously believed in the areas that we examined. Rather, our results indicate that the impact of cancer on young adults may be more specific.

Contrary to our expectations, young adults' QoL scores and level of unmet needs were comparable to their older counterparts on most domains except for social functioning, financial problems, sexuality and health information needs, where young adults reported significantly higher levels of morbidity. It is possible that young adults have more active social lives than older adults. The lower levels of social functioning reported by young adult survivors could reflect an impaired ability to fulfill their usual social activities due to the effects of cancer. Secondly, previous research has reported that young adult cancer survivors experience feelings of isolation, which is more pronounced amongst those who did not know another young adult cancer survivor [20]. Arguably there is a need to develop and evaluate age-specific social support strategies for young adult cancer survivors [38].

Although our sample of young adults reported significantly higher income than their older counterparts, they also reported significantly higher levels of financial burden. This difference in financial burden is consistent with previous research [7] and is most likely due to the substantial financial obligations of young adults relative to older adults. Specifically, young adults are more likely to be in debt, caring for dependent children and less likely to be financially independent or have private health insurance compared to their older counterparts [39, 40]. These findings emphasize the considerable financial impact that a cancer diagnosis has on young adults, and consequently, financial support that is targeted to the specific needs of this population is warranted.

Our young adult cancer survivors also reported higher levels of sexuality, health system and information needs. Previous research has also reported high levels of unmet need for young adults in the areas of sexuality and intimacy counseling and for age-appropriate information [41]. Both of these needs could be attributed to the unique developmental stage of young adults. For instance, the physical side-effects of cancer and its treatment, such as early menopause, infertility and impotency [42], may have a greater impact on the sexuality of young adults as they are often starting or expanding their family, or may be in the early stages of developing an intimate relationship. It is important that age-appropriate resources are made available to young adult cancer survivors as well as appropriate support for sexuality issues.

Surprisingly, young adult cancer survivors reported comparable levels of alcohol consumption to older adults. Although not statistically significant, more young adult cancer survivors reported engaging in positive health behaviors than age-related peers in the areas of alcohol and smoking. This finding is consistent with some research which suggests that some cancer survivors may lead healthier lifestyles than cancer-free peers [43]. However, young adult cancer survivors were more likely to be current smokers compared to their older counterparts and less likely to engage in sufficient levels of physical activity compared to age-related peers. Although lower levels of physical activity may be explained by post-treatment side effects, it is essential that health care providers are aware of this potential discrepancy and offer appropriate support as evidence suggests that physical activity during and after treatment may be beneficial for some cancer patients [12]. Given the association between lifestyle behaviors and quality of life, side effects and risk of cancer recurrence, it is vital that health care professionals discuss health behaviors with their patients. It is likely that the prevalence of health risk behaviors is under-reported in this study given that self report surveys of this nature are open to social desirability bias.

Due to methodological differences, only crude comparisons were made between young adult cancer survivors and young adults from the general population and therefore should be considered a preliminary exploration only. The age-range of our young adults sample was not a direct match with the age-groupings used in the general population samples [24, 25]. We selected those aged 30-39 years in the Australian National Drug Strategy Household [24] Survey and 35-44 years in the NSW Population Health Survey [25] as the most appropriate comparison groups as 84.5% of young adults in our study were aged between 30 and 40 years. The levels of smoking and physical activity reported by these samples from the general Australian population is fairly similar to that reported by cancer-free 18-40 year olds in a large scale American population-based study [18]. Although there may be cultural differences between these samples, the large sample sizes and the similar definitions of smoking and sufficient physical activity suggest that while our comparisons are not ideal, they are appropriate given the available data.

We assessed alcohol consumption over the last six months whereas the National Drug Strategy Household Survey assessed alcohol consumption over the previous 12 months [24]. We also assessed participant's physical activity via pen and paper survey whilst the NSW Health Survey utilized a CATI [25]. It is important that future research investigates the health behaviors of young adult cancer survivors compared to their peers using directly comparable methodologies.

While we were able to compare the health behaviors of young adult cancer survivors with their peers, we were not able to do so for the psychosocial outcomes. This was due to the use

of cancer-specific measures. It is strongly recommended that future research employs general measures of unmet needs and QoL to assess the differences between young adult cancer survivors and their peers.

Although we included all of the young adults enrolled in the *Cancer Survival Study*, the sample size is small (n=58), thereby increasing the probability of a Type II error. The small sample size limited our ability to test the effect of covariates which could have contributed to some of the differences we found between groups, however we did attempt to control for some by matching the older sample of cancer survivors for gender and cancer type. Although the definition of young adults used in this study is based on that used by the National Cancer Institute [22], it would be beneficial if future research examined narrower age ranges such as 18-25 years and 26-40 years, as there may be significant variation within this population [22]. As data relating to response rates by age group were not available for the main study, we are unable to comment on any response bias that may exist between younger and older cancer survivors participating in this study. However, the overall sample of the *Cancer Survival Study* is representative of the Australian population diagnosed with cancer.

Despite selecting our participants from a population-based sample of the highest eight incident cancers in Australia, our sample did not represent the wider population of young adult cancer survivors in terms of cancer type; only two of the most prevalent cancer types (melanoma and Non-Hodgkin's lymphoma) diagnosed in young adults [39] were included. Young adults in a coupled relationship (82%) were also over-represented compared to the wider population of young Australian adults aged 18-24 and 25-34 in a coupled relationship (approximately 16% and 60%, respectively) [44], which may have led to higher levels of QoL being reported given the positive impact of social support on QoL [45].

The needs assessment tool (SCNS-SF34) employed in the larger study was designed as a generic measure applicable to the diversity of cancer survivors. Given that young adulthood is a unique developmental period, the use of the SCNS-SF34 in studies focusing solely on this group may neglect to identify important concerns specific to young adulthood. We recommend that future research strives to develop or validate a needs assessment measure which is specific to young adult cancer survivors.

To our knowledge this is the first population-based study exploring both the psychosocial outcomes and health behaviours of young Australian adults diagnosed with a diversity of cancer types. Despite the limitations of this study, it provides important information on the unique experiences and health behaviors of a population of cancer patients that has been overlooked. Results suggest that young Australian adults are impacted considerably by a diagnosis of cancer across a number of different areas of life. Specifically, this study provides a platform for future research which should utilize larger sample sizes to further investigate the impact of cancer on young adults' social, financial, sexual and informational domains of life. Although our study illustrates that some health behaviors of young Australian adult cancer survivors may be similar to their peers, health care professionals should not overlook the possibility of young adult cancer survivors engaging in higher levels of risky behaviors that could impact on their long-term survival and QoL.

## **ACKNOWLEDGEMENTS**

This project was undertaken by the Cancer Council New South Wales' Centre for Health Research & Psycho-oncology (CHeRP). The research on which this paper is based was conducted as part of the *Cancer Survival Study*. We are grateful to the National Health & Medical Research Council (ID 252418), Cancer Council NSW, Hunter Medical Research Institute, Honda Foundation and University of Newcastle for funding; Victorian Cancer Registry (Cancer Council Victoria) and NSW Central Cancer Registry (NSW Department of Health and Cancer Institute NSW) for assistance with case recruitment, and to the cancer survivors who provided the survey data. We would also like to acknowledge Alison Zucca for her assistance in data collection and Christophe Lecathelinais for statistical assistance.

## **COMPETING INTERESTS**

The authors declare that they have no competing interests. The Centre for Health Research & Psycho-oncology (CHeRP) has full control of all primary data and as such agree to allow the journal to review the data relating to this paper if requested.

## REFERENCES

1. Annertz K, Anderson H, Biorklund A, Moller T, Kantola S, Mork J, Olsen JH, Wennerberg J (2002) Incidence and survival of squamous cell carcinoma of the tongue in Scandinavia with special reference to young adults. *Int. J. Cancer* 101:95-99. doi: 10.1002/ijc.10577
2. Shiboski CH, Schmidt BL, Jordan RCK (2005) Tongue and tonsil carcinoma: Increasing trends in the U.S. population ages 20-44 years. *Cancer* 103:1843-1849. doi: 10.1002/cncr.20998
3. Siegel RL, Jemal A, Ward EM (2009) Increase in incidence of colorectal cancer among young men and women in the United States. *Cancer Epidemiol Biomarkers Prev* 18:1695-1698. doi: 10.1158/1055-9965.EPI-09-0186
4. Australian Institute of health and Welfare (AIHW). Number of new cases and age specific rates by year, sex and 5 year age groups, Australia, 1982-2005. [http://d01.aihw.gov.au/cognos/cgi-bin/ppdscgi.exe?DC=Q&E=/Cancer/australia\\_age\\_specific\\_1982\\_2005](http://d01.aihw.gov.au/cognos/cgi-bin/ppdscgi.exe?DC=Q&E=/Cancer/australia_age_specific_1982_2005). Accessed March 2010.
5. Wenzel LB, Fairclough DL, Brady MJ, et al (2003) Age-Related Differences in the Quality of Life of Breast Carcinoma Patients after Treatment. *Cancer* 86:1768-1774.
6. Parker PA, Baile WF, Moor CD, Cohen L (2003) Psychosocial and demographic predictors of quality of life in a large sample of cancer patients. *Psycho-Oncology* 12:183-193. doi: 10.1002/pon.635
7. Harrison J, Maguire P (1995) Influence of age on psychological adjustment to cancer. *Psycho-Oncology* 4:33-38.
8. King MT, Kenny P, Shiell A, Hall J, Boyages J (2000) Quality of Life Three Months and One Year after First Treatment for Early Stage Breast Cancer: Influence of Treatment and Patient Characteristics. *Quality of Life Research* 9:789-800.
9. Mor V, Allen S, Malin M (1994) The psychosocial impact of cancer on older versus younger patients and their families. *Cancer* 74:2118-2127.
10. Kroenke CH, Rosner B, Chen WY et al (2004) Functional impact of breast cancer by age at diagnosis. *J Clin Oncol* 22:1849-1856. doi: 10.1200/JCO.2004.04.173
11. Jones LW, Demark-Wahnefried W (2006) Diet, exercise, and complementary therapies after primary treatment for cancer. *Lancet Oncol* 7:1017-1026.
12. Brown JK, Byers T, Doyle C et al (2003) Nutrition and Physical Activity During and After Cancer Treatment: An American Cancer Society Guide for Informed Choices. *CA Cancer J Clin* 53:268-291. doi: 10.3322/canjclin.53.5.268
13. Blanchard CM, Courneya KS, Stein K (2008) Cancer survivors' adherence to lifestyle behavior recommendations and associations with health-related quality of life: results from the American Cancer Society's SCS-II. *J Clin Oncol* 26:2198-2204. doi: 10.1200/JCO.2007.14.6217
14. World Cancer Research Fund/American Institute for Cancer Research. Food, nutrition, physical activity, and the prevention of cancer: a Global Perspective. Washington DC: AICR; 2007.
15. Scollo MM, Winstanley MH: Tobacco in Australia and Issues. Melbourne: Cancer Council Victoria, 2008.
16. Australian Medical Association (AMA). Alcohol use and harms in Australia. In AMA- Information paper. Canberra: Australian Medical Association, 2009.
17. Eakin EG, Youlden DR, Baade PD et al (2007) Health behaviors of cancer survivors: data from an Australian population-based survey. *Cancer Causes Control* 18:881-894. doi: 10.1007/s10552-007-9033-5

18. Bellizzi KM, Rowland JH, Jeffery DD, McNeel T (2005) Health behaviors of cancer survivors: examining opportunities for cancer control intervention. *J Clin Oncol* 34:8884-8893. doi: 10.1200/JCO.2005.02.2343
19. Caspersen CJ, Pereira MA, Curran KM (2000) Changes in physical activity patterns in the United States, by sex and cross-sectional age. *Medicine & Science in Sports & Exercise* 32:1601-1609.
20. Dunn J, Steginga SK (2000) Young women's experience of breast cancer: Defining young and identifying concerns. *Psycho-Oncology* 9:137-146.
21. Siegel K, Gluhoskib V, Goreyc E (1999) Age-related distress among young women with breast cancer. *Journal of Psychosocial Oncology* 17:1-20. doi: 10.1300/J077v17n01\_01
22. Bethesda MD, U.S. Department of Health and Human Services, National Institutes of Health, National Cancer Institute, Livestrong Young Adult Alliance (2006) Closing the gap: Research and care imperatives for adolescents and young adults with cancer. NIH publication No. 06-6067.
23. Boyes AW, Girgis A, Zucca AC (2009) "It's been a journey, I am a survivor": Changes in psychosocial wellbeing over the first 12 months since a cancer diagnosis. *Asia Pacific Journal of Clinical Oncology* 5:A157.
24. Australian Institute of Health and Welfare. 2007 National Drug Strategy Household Survey: first results. In *Drug Statistics Series*. Canberra: Australian Institute of Health and Welfare, 2008.
25. Centre for Epidemiology and Research. *2008 Report on Adult Health from the New South Wales Population Health Survey*. Sydney: NSW Department of Health; 2009.
26. Aaronson NK, Ahmedzai S, Bergman B et al (1993) The European Organization for Research and Treatment of Cancer QLQ-C30: A quality-of-life instrument for use in international clinical trials in oncology. *Journal of National Cancer Institute* 85:365-376.
27. Fayers PM, Aaronson NK, Bjordal K, Groenvold M, Curran D, Bottomley A. *EORTC QLQ-C30 Scoring Manual (3rd edition)*. Brussels: EORTC; 2001.
28. Boyes A, Girgis A, Lecathelinais, C (2009) Brief assessment of adult cancer patients' perceived needs: Development and validation of the 34-item Supportive Care Needs Survey (SCNS-SF34). *Journal of Evaluation in Clinical Practice* 15:602-606. doi: 10.1111/j.1365-2753.2008.01057
29. McElduff P, Boyes A, Zucca A, Girgis A: *The Supportive Care Needs Survey: A guide to administration scoring and analysis*. Newcastle: Centre for Health Research & Psycho-Oncology, 2004.
30. Australian Institute of Health and Welfare (AIHW). *National Health Data Dictionary, Version 8.0*. Canberra: Australian Institute of Health and Welfare, 1999.
31. Australian Institute of Health and Welfare (AIHW). 2001 National Drug Strategy Household Survey: Detailed findings. In *Drug Statistics Series No11*. Canberra: Australian Institute of Health and Welfare; 2002:1-118.
32. National Health and Medical Research Council (NHMRC). *Australian Guidelines: To reduce health risks from drinking alcohol*. Canberra: National Health and Medical Research Council, 2009.
33. National Health and Medical Research Council (NHMRC): *Australian alcohol guidelines: health risks and benefits*. Canberra: National Health and Medical Research Council; 2001 (REVOKED).
34. Toumbourou JW, Hemphill SA, McMorris BJ, Catalano RF, Patton GC (2009) Alcohol use and related harms in school students in the USA and Australia. *Health Promotion International* 24:373-382. doi: 10.1093/heapro/dap037

35. Australian Institute of Health and Welfare (AIHW). The Active Australia Survey: A guide and manual for implementation, analysis and reporting. Canberra: Australian Institute of Health and Welfare; 2003.
36. Osoba D, Rodrigues G, Myles J, Zee B, Pater J (1998) Interpreting the significance of changes in health related quality of life scores. *J Clin Oncol* 16:139-144.
37. Sloan JA, Cella D, Frost MH, et al (2002) Assessing clinical significance in measuring oncology patient quality of life: Introduction to the symposium, content overview, and definition of terms. *Mayo Clin Proc* 77:367-370.
38. Treadgold CL, Kuperberg A (2010) Been there, done that, wrote the blog: the choices and challenges of supporting adolescents and young adults with cancer. *J Clin Oncol*. doi: 10.1200/JCO.2009.23.0516
39. Bleyer A (2005) The Adolescent and Young Adult Gap in Cancer Care and Outcome. *Curr Probl in Paediatr Adolesc Health Care* 35:182-217 doi: 10.1016/j.cppeds.2005.02.001
40. Australian Bureau of Statistics. *Household Debt: In Australian Social Trends 2009*. Canberra: Australian Bureau of Statistics, 2009.
41. Zebrack BJ (2009) Information and service needs for young adult cancer survivors. *Support Care Cancer* 17:349-357. doi: 10.1007/s00520-008-0435-z
42. Schover SR (2005) Sexuality and fertility after cancer. *Hematology/Oncology Clinics of North America* 523-527.
43. Larcombe I, Mott M, Hunt L (2002) Lifestyle behaviours of young adult survivors of childhood cancer. *British Journal of Cancer* 87:1204-1209. doi: 10.1038/sj.bjc.6600632
44. Australian Bureau of Statistics. *Marriages and Divorces: In Australian Social Trends 2009*. Canberra: Australian Bureau of Statistics, 2009.
45. Hogan BE, Wolfgang L, Najarian B (2002) Social support interventions do they work? *Clinical Psychology Review* 22:381-440.

Table 1: Demographic and disease characteristics of young and older adult cancer survivors

Characteristics	Survey sample of young adults aged 18-40 (N = 58)		Survey sample of older adults aged 64+ (N = 58)	
	n	%	N	%
Gender				
Female	41	70.7	41	70.7
Male	17	29.3	17	29.3
Marital status				
Partnered (married or defacto)	48	82.8	45	77.6
Single (widowed, separated, single)	10	17.2	13	22.4
Education*				
University or Technical College	40	69.0	23	39.7
High school or less	18	31.0	35	60.3
Health Insurance Status †				
Medicare only	21	36.8	24	41.4
Private	36	63.2	34	58.6
Weekly gross family income*†				
Less than \$500	6	13.0	29	67.4
More than or equal to \$500	40	87.0	14	32.6
Current paid employment*†				
Yes	36	63.2	6	10.5
No	21	36.8	51	89.5
Cancer type				
Melanoma	21	36.2	21	36.2
Breast	15	25.9	15	25.9
Non-Hodgkin's Lymphoma	12	20.7	12	20.7
Leukemia	6	10.3	6	10.3
Other	4	6.9	4	6.9
Extent of disease at diagnosis				
Early/less progressed	27	46.6	28	48.3
Later/more progressed	10	17.2	7	12.1
Not applicable/unknown	21	36.2	23	39.7
Treatment in the last month				
Active (chemotherapy, surgery, radiotherapy, bone marrow transplant )	19	32.8	12	20.7
Passive (hormone treatment, immunotherapy)	3	5.2	10	17.2
No treatment	36	62.1	36	62.1
Co-morbidity				
Yes	18	34.0	20	38.5
No	35	66.0	32	61.5

\* $P < .01$ 

† Total greater than the sum of the columns due to missing values.

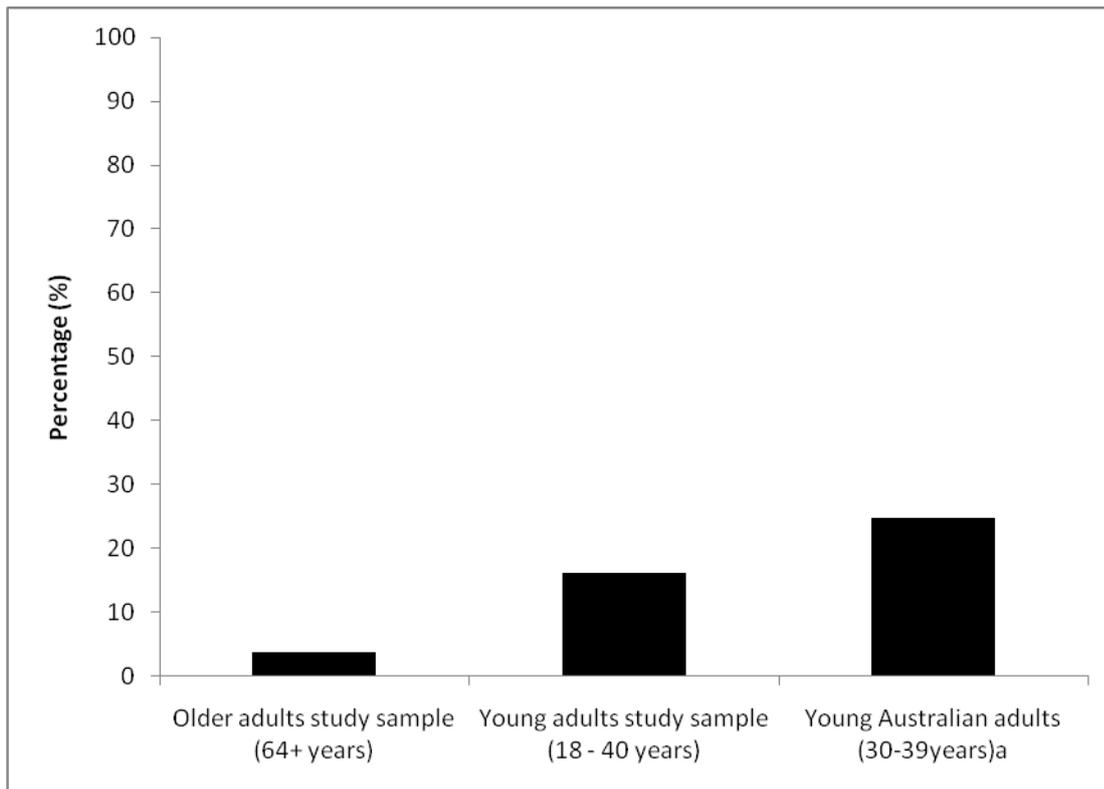
Table 2: Standardized QoL scores for young and older adult cancer survivors

	Young Adults (N=58)			Older Adults (N=58)			Difference in Mean Scores*
	Mean	Std Dev	Range	Mean	Std Dev	Range	
<b>Global</b>	71.1	20.5	25-100	68.8	21.2	0-100	2.3
<b>Functional Scales</b>							
Physical	88.0	15.5	40-100	78.4	21.1	13.3-100	9.6
Social	76.4	30.1	0-100	84.2	25.8	0-100	7.8
Emotional	74.5	23.5	8.3-100	79.7	19.6	16.7-100	5.2
Role	78.2	29.7	0-100	83.0	22.4	16.7-100	4.8
Cognitive	81.9	23.6	0-100	81.0	19.6	16.7-100	0.9
<b>Symptom Scales</b>							
Financial Difficulties	28.2	36.8	0-100	12.1	23.1	0-100	16.1
Constipation	6.3	13.2	0-33.3	11.5	21.2	0-100	5.2
Appetite Loss	12.6	24.0	0-100	8.6	17.2	0-66.7	4.0
Fatigue	33.3	27.5	0-100	30.5	21.5	0-100	2.8
Pain	16.4	20.1	0-100	14.1	22.7	0-83.3	2.3
Dyspnoea	15.5	25.1	0-100	17.8	25.9	0-100	2.3
Insomnia	30.5	30.8	0-100	32.8	28.9	0-100	2.3
Nausea and Vomiting	5.7	11.1	0-50	4.3	8.0	0-33.3	1.4
Diarrhea	7.5	15.3	0-66.7	6.9	18.5	0-100	0.6

\* Clinically significant differences in mean QoL scale scores are represented as small (5-10 points), moderate (10-20 points) and large ( $\geq 20$  points) clinically significant differences

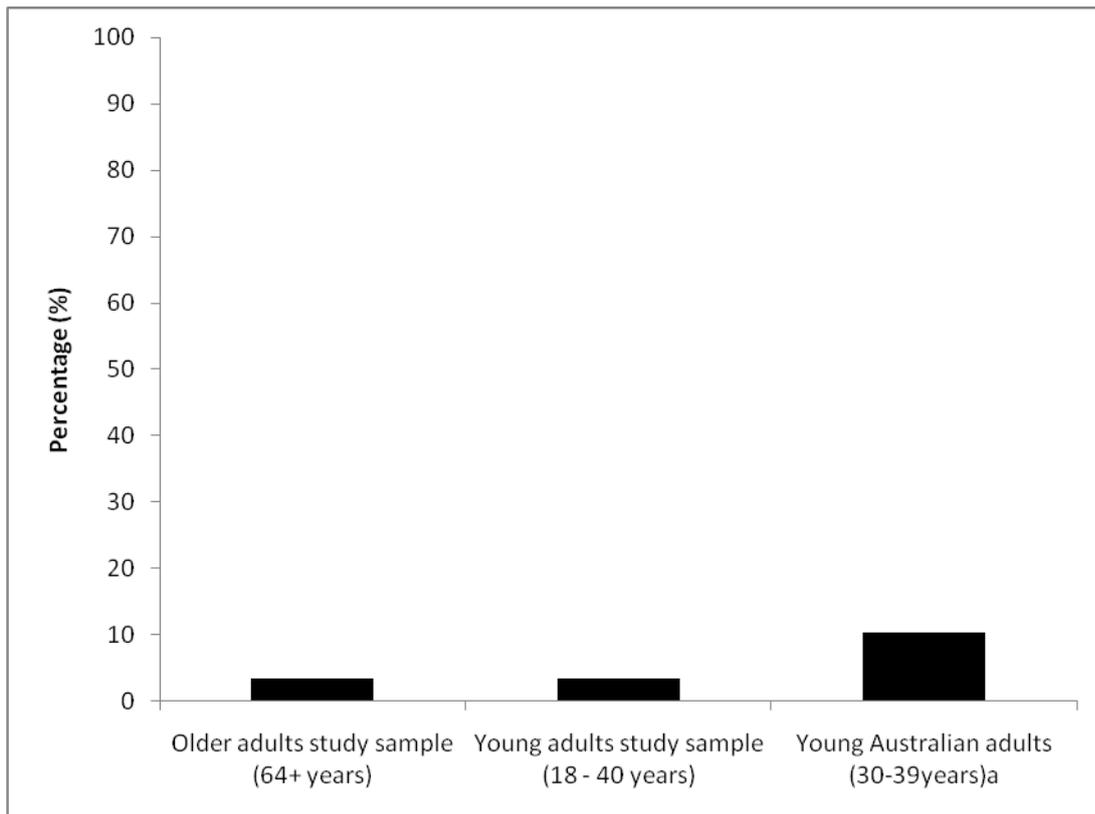
Table 3: Top five moderate/high unmet needs reported in the last month by young adult cancer survivors compared to the older adult cancer survivors

<b>Rank</b>	<b>Item</b>	<b>Domain</b>	<b>Young adults reporting a moderate/high need (n=58) N</b>	<b>Young adults reporting a moderate/high need (n=58) % (95% CI)</b>	<b>Older adults reporting a moderate/high need (n=58) N</b>	<b>Older adults reporting a moderate/high need (n=58) % (95% CI)</b>	<b>P</b>
1	Fears about the cancer spreading	Psychological	12	20.7% (10.1%, 31.3%)	6	10.9% (2.5%, 19.3%)	0.16
1	Uncertainty about the future	Psychological	12	20.7% (10.1%, 31.3%)	2	3.6% (0.0%, 8.5%)	0.01
2	Concerns about the worries of those close to you	Psychological	11	19.0% (8.7%, 29.2%)	6	10.7% (2.5%, 18.9%)	0.22
3	Anxiety	Psychological	10	17.2% (7.4%, 27.1%)	5	9.1% (1.4%, 16.8%)	0.20
4	Lack of energy	Physical and daily living domain	9	15.5% (6.1%, 25.0%)	3	5.5% (0%, 11.5%)	0.08
5	Worry that treatment is beyond your control	Psychological	8	13.8% (4.8%, 22.8%)	3	5.4% (0.0%, 11.3%)	0.13



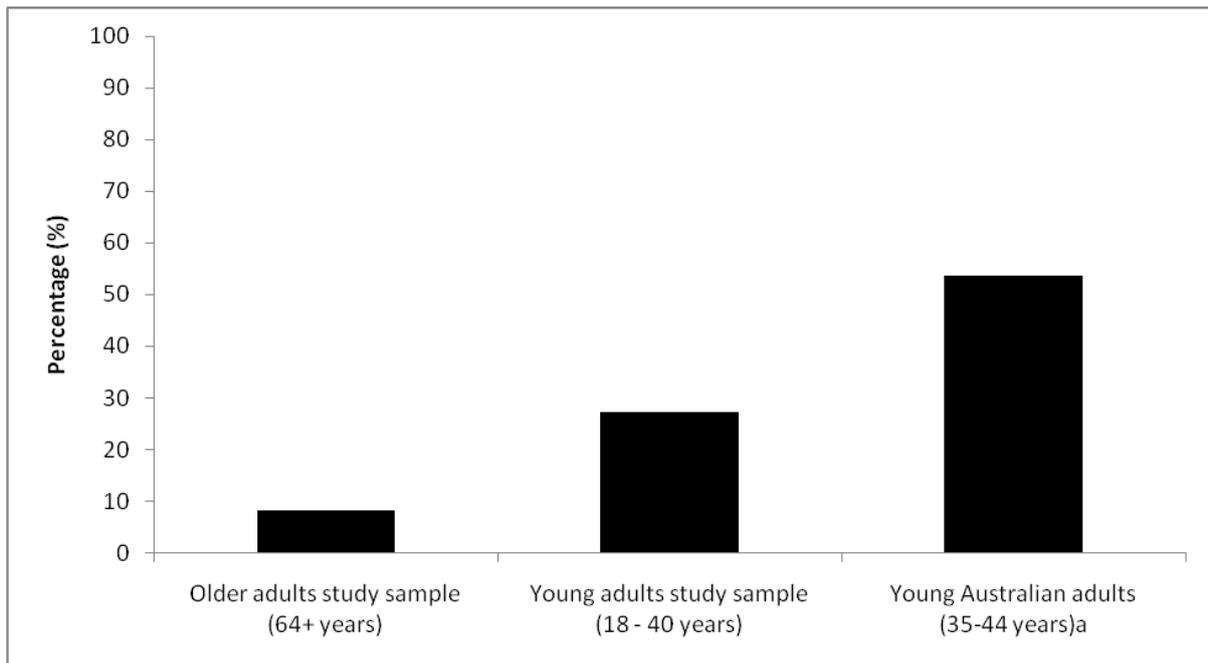
**Fig.1** Percentage of young adult cancer survivors who reported being a ‘current smoker’ compared to older adult cancer survivors and young adults from the Australian general population

- a. Population data from: Australian Institute of Health and Welfare. 2007 National Drug Strategy Household Survey: first results. In *Drug Statistics Series*. Canberra: Australian Institute of Health and Welfare, 2008 [24]



**Fig.2** Percentage of young adult cancer survivors classified as as consuming alcohol at a 'high risk/risky,' level compared to older adult cancer survivors and young adults from the Australian general population

- a. Population data from: Australian Institute of Health and Welfare. 2007 National Drug Strategy Household Survey: first results. In *Drug Statistics Series*. Canberra: Australian Institute of Health and Welfare, 2008 [24]



**Fig.3** Percentage of young adult cancer survivors achieving 'sufficient' levels of physical activity compared to older adult cancer survivors and young adults from the NSW general population

- a. Population data from: Centre for Epidemiology and Research. *2008 Report on Adult Health from the New South Wales Population Health Survey*. Sydney: NSW Department of Health; 2009 [25]