

Financial challenges of cancer for adolescents and young adults and their parent caregivers

Robyn J McNeil, MPH, Centre for Adolescent Health, Murdoch Children's Research Institute (MCRI);

Maria McCarthy, PhD, Social and Mental Health Aspects of Illness, MCRI;

David Dunt, PhD, School of Population and Global health, University of Melbourne;

Kate Thompson, MASW, OnTrac at Peter Mac Victorian Adolescent and Young Adult Cancer Service;

Silja Kosola, MD PhD, Pediatric Research Center, Helsinki Children's Hospital and University of Helsinki;

Lisa Orme, MD PhD, OnTrac at Peter Mac Victorian Adolescent and Young Adult Cancer Service;

Sarah Drew (deceased), Centre for Adolescent Health, Department of Pediatrics, University of Melbourne;

Susan Sawyer, MD PhD, Centre for Adolescent Health, MCRI.

Address correspondence to Robyn J. McNeil, Centre for Adolescent Health, MCRI, 50 Flemington Road, Parkville, VIC 3052, Australia

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Abstract

This study examined the financial impact of cancer and the use of income support in adolescents and young adults (AYAs) with cancer and their parent caregivers.

As part of a national Australian study exploring the psychosocial impacts of cancer, 196 AYAs aged 15-25 years, 6-24 months from diagnosis, and 204 parent caregivers from 18 cancer sites were surveyed. Logistic regression and Chi square analyses were conducted to assess the influence of clinical and socio-demographic variables on financial status.

Qualitative responses were coded and key themes were identified using thematic analysis.

The findings indicate that more than half of AYAs and parents reported financial issues as a consequence of AYA cancer. Financial issues resulted from direct medical costs, associated costs from treatment, and indirect costs from loss of income. AYAs and parents reported that it was important for them to receive income support, both during and after cancer treatment.

However large proportions of those who reported needing income support had difficulty accessing it.

AYAs and their families are substantially financially disadvantaged by cancer, many for a prolonged time. Patient and family centered assessments and interventions are required to reduce the financial burden of AYA cancer.

Keywords: Cancer, Financial Burden, AYAs, Income Support, Patient Experience, Psychosocial Impacts

INTRODUCTION

The diagnosis of cancer during adolescence and young adulthood signals the potential for major disruption of normal developmental trajectories (Grinyer, 2007; Sawyer et al., 2012; Zebrack, 2011). At the time when most adolescents and young adults (AYAs) are engaged in education and training, exploring and establishing career choices, and have yet to gain financial independence, cancer treatment has the potential to profoundly affect education and employment pathways (Grinyer, 2007; Thompson, Palmer, & Dyson, 2009; Zebrack, 2011) with ramifications for health (Patton et al., 2016), and emotional and economic wellbeing (D'Agostino, Penney, & Zebrack, 2011; Hall et al., 2012; Yabroff et al., 2016).

The extent of the financial burden from cancer is increasingly recognised in adults, with three broad categories of costs described; the 'financial toxicity' from the direct costs of cancer and its treatment (Zafar et al., 2013), even for those with medical insurance (Longo, Fitch, Deber, & Williams, 2006; Markman & Luce, 2010; Zafar et al., 2013); treatment-related out-of-pocket expenses (e.g., transport to attend treatment, food, accommodation, car parking); and indirect costs including loss of income from being unable to work (Aaronson et al., 2014; Guy et al., 2013; Kim, 2007; Longo et al., 2006). The financial burden associated with inability or partial return to work is not simply a feature of the acute treatment phase, but has been shown to last up to 10 years after diagnosis (Bloom, 2002; Mehnert, 2011; Paalman et al., 2016). In contrast to the financial impacts on adult patients, the pediatric literature indicates that it is families of children with cancer who experience significant financial burden during treatment as well as after treatment ends, and includes direct and indirect costs. Families of children living in rural and regional areas have been found to incur higher overall out-of-pocket costs for cancer treatment, particularly around transport and accommodation. (Cohn, Goodenough, Foreman, & Suneson, 2003). In Australia, where around a third of new cancers arise in patients from rural, regional and remote regions, the distances patients must

travel to access care at cancer centres makes this issue particularly pertinent (Australian Institute of Health and Welfare & Australian Association of Cancer Registries, 2007).

Direct and indirect costs are compounded by the loss of family income when a parent gives up work to care for their child with cancer (Eiser & Upton, 2007; Heath, Lintuuran, Rigguto, Tikotlian, & McCarthy, 2006; Wakefield, McLoone, Evans, Ellis, & Cohn, 2014). These impacts are likely to be compounded for families with fewer financial reserves to draw upon.

Few studies have examined the financial experiences and impacts of AYAs with cancer (D'Agostino et al., 2011). Studies from the United States have focussed on medical costs and insurance issues related to the US healthcare system (Freyer & Barr, 2007; Zebrack et al., 2014) for 15 to 39 year old individuals. The breadth of this age span comprises AYAs with a diversity of education and employment needs, including those who are only just embarking on their careers with few individual financial reserves, as well as those with established careers and potentially greater financial security (D'Agostino et al., 2011; Geue et al., 2014; Hall et al., 2012). In addition, the US healthcare system differs significantly from Australia; Australia has a universal health care system that provides comprehensive cancer care in public health services which theoretically should minimize medical costs associated with cancer treatment. This system includes a parallel model of healthcare involving patients purchasing private healthcare for services. Until recently, it has been unclear how the use of the private model or a combination of public/private services impacts financial outcomes from cancer treatment, although some research indicates that direct medical costs can be significant for adult cancer patients using private health care (Cohn, Goodenough, Foreman, & Suneson, 2003; Gordon et al., 2017).

The United Kingdom (UK) and Australia have developed specialist AYA cancer services for young people aged from 13 years (UK) and 15 years (Australia) to the mid-twenties (Osborn, Little, Bowering, & Orme, 2013; Teenage Cancer Trust, 2015), a period of

formative transitions from within education, from education to employment, and from financial dependence on family towards relative independence. Disruption during these critical years can be appreciated to have a different salience than for older adults with more established employment track records and greater financial assets. This narrower age span also includes the years in which many parents continue to support AYAs physically, emotionally and financially (D'Agostino et al., 2011; Wakefield, McLoone, Butow, Lenthen, & Cohn, 2013). This raises questions about to what extent families might be financially impacted by the experience of cancer in their AYA children. We hypothesise that the financial impact of cancer on families would be similar to paediatric studies, and greater for those in regional, rural and remote areas as well as in families of lower income or with less financial reserves (Heath et al., 2006).

This study aimed to examine the financial impact of cancer for AYAs aged 15-25 years and their parent caregivers in Australia, including whether clinical and socio-demographic factors identified in extant literature were associated with these outcomes. A second aim was to examine AYA and parent caregiver experiences in terms of (i) their need for income support and (ii) the challenges associated with accessing this support.

METHODS

The Youth Friendly Cancer Care project is a four-stage sequential strategy of inquiry undertaken to determine the degree to which Australian cancer services are meeting the needs of AYAs and their parents. This paper uses data from stage three, a nationally representative survey of AYAs and their parents, of which detailed methods have been reported (Sawyer et al., 2016). Australia has both universal health care and a social support system, both of which would be hypothesized to buffer families from the financial costs of cancer. The context of

the Australian healthcare system and its approach to income support is briefly summarized in Panel 1.

[Insert Figure 1 here]

Participants

Eligible AYAs were: (i) 15-25 years old with a cancer diagnosis (including relapsed or second cancers) between September 2010 and December 2012; and (ii) 6-24 months from diagnosis. Exclusion criteria were: (i) inability to complete the survey due to poor literacy in English, cognitive deficit or being too unwell; and (ii) Stage 1 and 2 melanoma (as these involve brief surgical treatment only). Parent caregivers were identified if they were nominated by the AYA, or listed as the nominated primary parent in hospital databases.

Procedure

Twenty-one hospitals providing AYA cancer care across Australia were approached, of which 17 (12 adult and 5 pediatric hospitals) agreed to participate, together with one charitable AYA cancer organization, CanTeen. Ethics and governance approvals were obtained from each site. Potentially eligible participants were identified by local staff using clinical databases and mailed a survey package. Parent contact details were not available at seven adult hospitals, or from the CanTeen database. In these instances, packages were mailed to the AYA with the request to forward the survey to a nominated parent. Response rates were conservatively estimated to be 25.7% and 27.3% for AYAs and parents respectively (Sawyer et al., 2016).

Measures

The AYA survey comprised a 70-item self-administered questionnaire that included a combination of validated psychosocial measures and study-specific items that were developed from the literature and our earlier qualitative analysis of AYA and parent interviews (Sawyer et al., 2016). Survey items relating to financial burden examined two key

areas: i) the financial impact of cancer and ii) use of income support. The surveys included space for open-ended commentary. These questions were replicated in the self-administered parent surveys to similarly explore the financial impact on parents.

Financial burden

Two single item questions from the Psychosocial Assessment Tool (PAT) (Pai et al., 2008) were used to assess the financial costs experienced by participants: “*Did you experience any financial difficulties as a consequence of your cancer diagnosis and treatment?*” and “*In what areas have you experienced financial difficulties while you have been receiving treatment?*”. For the former, the responses options were “*No*”, “*Yes, some financial problems*”, “*Yes, many financial problems*”, “*Yes, it’s hard to meet our basic needs*” and “*I don’t know*”. For the latter, response options eight areas of impact were (“*Phone/utility bills*”, “*Rent/mortgage*”, “*Buying food*”, “*Vehicle related [upkeep/petrol/insurance]*”, “*Medical expenses*”, “*Parking at the main cancer treatment centre*”, “*Having to pay for television while an inpatient at the main cancer treatment centre*”, and “*Other*”).

Income Support

Two single-item questions with Likert response scales were used to explore the need for, and challenges associated with, accessing income support both during and after treatment: “*Was it important for you to receive income support from the government?*” and “*Did you experience difficulties/challenges getting access to income support from the government?*”. Response options for the former were “*Yes, very important*”, “*Yes, somewhat important*”, “*No, not important*”, and “*Not applicable*”. For the latter, response options were, “*Yes, very important*”, “*Yes, somewhat important*”, “*No, not important*”, and “*Not applicable*”. All response options were dichotomized to “*Yes*” and “*No*” for analysis. Not applicable options were omitted.

Educational and work impact

AYAs were asked a single-item question which was utilized as a proxy indicator of current work and financial capacity: “*At the current time, have you been able to get back on track with work plans and activities?*” Response options were “*Yes*”, “*No*”, “*To some extent*” and “*Not applicable*”.

Demographic and clinical variables

A number of sociodemographic and clinical variables were hypothesized from the adult and paediatric literature to be associated with financial difficulties and the need for income support. For AYAs these include: older age at diagnosis, being unemployed, living outside the family home, and living in a regional/rural area. For parents these include: a younger AYA age at diagnosis, AYA living in the family home, living in a regional/rural area, a blood cancer diagnosis and length of stay in hospital. In the absence of family income assessment, the research team used parent education attainment as a proxy indicator of income.

Statistical Analysis

Quantitative analyses were conducted using STATA version 13 (StataCorp, 2013).

Demographic, clinical, financial burden and income support for AYAs and parents were characterised using descriptive analyses. A number of sociodemographic and clinical variables were dichotomised to simplify data analysis. Differences between groups were analysed by Chi square analyses; significance level (α) was less than or equal to 5% (0.05).

Logistic regression analyses were conducted to test associations between sociodemographic and clinical characteristics. Results are reported in odds ratios (OR) with 95% confidence intervals (CI). Multi-collinearity between independent variables in the regression models was assessed using variance inflation factor (VIF) and all found to be acceptable at less than 1.8 (O’Brien, 2007).

Qualitative responses to open-ended questions were coded using open and axial coding to summarize the text (Rice & Ezzy, 1999). Key themes were identified using inductive thematic analysis (Braun & Clarke, 2006).

RESULTS

The study sample consisted of 196 AYAs and 204 parents. The mean age at diagnosis was 19.9 years and the mean time since diagnosis was 19 months (SD 8.17). Fifty percent of AYAs were studying part- or full-time, 44% were working part- or full-time and 11% were unemployed at the time of the survey. AYA demographic and clinical details are shown in Table 1. Parent participants were predominantly mothers (89%). At the time of the survey, 70% of parents were working either part- or full-time. Demographic details of parent carers are shown in Table 2.

[Insert Tables 1 and 2 about here]

Financial Burden

Forty-five percent of AYAs (n=191) reported they had been able to ‘get back on track’ with work plans, 30% were back on track to some extent, while 15% reported they had not been able to get back on track. Comments indicated many were unable to function at their previous capacity due to fatigue, frequency of medical appointments or due to having changed career paths. More than half of AYAs (57%) reported financial issues as a consequence of their cancer diagnosis and treatment (Figure 2). Of those who reported financial issues, almost two thirds (63%) reported that they lived with their parents. More 20-25 year olds reported financial issues (64%) than 15-19 year olds (47%), and an older age (20-25 years) at diagnosis was associated with increased likelihood of financial issues (OR 1.98 [CI 1.06, 3.67] p=0.031). There was a reduced likelihood of having financial issues if the AYA was living in the family home (OR 0.5[CI 0.25, 0.98] p =0.044) in regression analyses. (Table 3).

Financial challenges for AYAs related to both ongoing costs of living and additional costs incurred from cancer treatment including vehicle-related costs (49%), medically-related costs (44%), utilities (40%) and car parking at the treatment centre (38%) (Figure 3). Their comments indicated financial burden was also from loss of income; *“I was unable to work for one whole year. I went back to work only because I needed the money”*

Almost two thirds (62%) of parents reported financial issues as a consequence of their child’s cancer (Figure 2). Logistic regressions indicated that parents who lived in a regional/rural area), parents of 15-19 year olds, and parents of AYAs whose inpatient stay was longer than one month were more likely to experience financial issues as a result of their child’s cancer. Parents whose child was living in the family home were more likely to experience financial difficulties, although this finding was not statistically significant (OR 2.91 [CI 1.0, 8.5] p=0.050) (Table 3).

For parents, areas of financial burden were similar to those described by AYAs: vehicle costs (40%); utilities (39%); medical expenses (29%); and mortgage repayments (27%) were each reported by substantial numbers of parents (Figure 3). Car parking at the treatment centre was the leading area of financial burden for parents (58%). While this was notably higher than for AYAs (38%), it was not statistically significant ($\chi^2 = 1.96$ p=0.16). Many comments related to the cost of transportation to the cancer centre. One parent said, *“The main cost was the toll road. We clocked up \$1800 for the year. Normal year \$50-\$60”*. Other comments acknowledged the impact of financially supporting their child who was unable to do so themselves, such as, *“Supporting him financially while he was off work for 6 months. He was living at home, not paying his usual board, and I was buying a lot of healthy food for him”*. However, the majority of parent commentary related to the impact of the direct loss of parent income *“high medical expenses and my loss of income has placed tremendous strain on our family's financial resources”*, particularly when parents were self-

employed. *“I am self employed and was unable to work for a substantial amount of time so I could be with my son”*. Analysis of comments suggested that many parents who were more able to manage financially had flexibility in their workplace (e.g. possibility of extended leave), supportive family or friends, and the safety net of accumulated savings. One parent stated, *“I had a lot of support from my parents-in-law and my boss. My father-in-law helped with transport to and from hospital on many occasions. My boss gave me flexibility with my work hours and I was also able to work from the hospital”*.

[Insert Table 3 about here]

Income support

Sixty-percent of AYAs reported it was important for them to receive income support *during* treatment and 48% reported it was important *after* treatment. Of those AYAs who needed income support *during* treatment, 77% also reported needing income support *after* treatment.

The need for income support for AYAs *during* treatment was significantly associated with older age at diagnosis and being unemployed (Table 4).

[Insert Table 4 about here]

Being unemployed was also associated with AYAs needing income support *after* treatment. AYAs who indicated they did not need government income support reported financial assistance from other sources, including pre-existing employment structures, income protection, parents and personal savings (Table 5).

[Insert Table 5 about here]

Thirty-eight percent of parents reported it was important to receive income support for themselves *during* their child’s treatment. Income support was significantly associated with parents who lived in a rural/regional area, whose child was younger (15-19 years) at diagnosis, had an inpatient stay of one month or longer, whose child was treated in a paediatric setting and whose child had a blood cancer compared to other types of cancer .

Parents who had a university education level had a reduced likelihood of requiring income support *during* treatment (Table 4).

After treatment, 26% of parents reported it was important for them to receive income support. Sixty-eight percent of parents who reported needing income support *during* treatment also reported needing income support *after* treatment. In regression analyses, income support *after* treatment was significantly associated with parents who lived in a rural/regional area, whose child was younger at diagnosis, who required a longer inpatient stay, and were treated in a pediatric setting (Table 5). Education attainment level data was not analysed for parents after treatment due to low numbers.

Difficulties accessing income support

Fifty-two percent of AYAs and 32% of parents reported difficulties accessing income support *during* treatment, while 37% of AYAs and 22% of parents reported difficulties *after* treatment. Seventy-four percent of AYAs who reported needing income support *during* treatment had difficulty accessing it (χ^2 : 54.08 $p < 0.001$), while 67% of AYAs who reported needing income support *after* treatment also reported difficulties (χ^2 : 64.00 $p < 0.001$). Similarly, of parents who reported needing income support, 70% reported challenges accessing it *during* their child's cancer treatment (χ^2 : 86.68 $p < 0.001$) and 62% of parents who reported needing income support *after* treatment reported challenges accessing it (χ^2 : 70.62 $p < 0.001$).

Qualitative analysis of AYA and parent comments in relation to income support revealed prominent issues related to the eligibility criteria of Centrelink (see Figure 1 for description). Many described confusion around eligibility as the diagnosis of cancer did not fit well with the criteria for any income support scheme. One AYA said, "*Centrelink was*

very difficult to organize as there was no specific payment for my circumstances, there was a lot of time involved to get Centrelink payments”.

Others were classified as eligible for an income support scheme that appeared inappropriate due to their health circumstances. One AYA said, *“Centrelink are keeping me on a Newstart [job seeking allowance] and making me regularly submit medical certificates to be exempt from job seeking requirements. Won't grant me disability [income support] and recognize my study as it is only part-time and I'm not well enough to work or study full time”.* These problems continued after treatment, especially when the AYA was unable to work but was no longer classified as being on active treatment. One said, *“During treatment I received income from Centrelink, but as soon as my treatment stopped (even though I could not work) Centrelink cut me off telling me to get a job, which was not possible”.*

A number of comments made by AYAs who had received government income support suggested it was not sufficient to cover their basic needs. One said, *“\$400 fortnight [from Centrelink] was barely enough to cover basic needs such as rent and petrol.”* Other AYAs reported they were ineligible for government assistance due to the strictness of eligibility requirements, such as them having some financial savings. One AYA reported, *“Centrelink would not support me with income, due to bank account savings”.*

A consistent theme within AYA and parent comments was the bureaucratic challenge of engaging with Centrelink. This included the extent of paperwork required, delays in processing applications, requests to present in person that were inappropriate for health reasons, and delays receiving financial assistance once deemed eligible. One AYA stated, *“We were given wrong information, sent on wild goose chases and no support. Documents needed 3-4 times. Even phoned on the day of the operation wanting more paperwork that had already been given 3 times.”* Many parents, including parents of 20-25 yr olds, commented on the extent to which they were required to help their child access income support; *“Long*

drawn out process, my daughter decided she didn't have energy to persevere so I started taking over on her behalf”.

Many parents made similar comments about the challenges accessing income support for themselves as carers, predominately due to carer eligibility criteria. One wrote, “*Centrelink withdrew their payment/support when my son turned 16. I felt that was unfair as I still had expenses with hospital appointments etc.*” Another said, “*Because of my income we were not eligible for Centrelink help, even though my wife had to give up work for 6 months to care for our daughter*”. Other comments suggested lack of knowledge about what income assistance may have been available; “*We did not receive any benefits from Centrelink - we were never made aware it was available*”.

DISCUSSION

This cohort study of Australian AYAs with cancer and their parent carers shows considerable financial impacts were experienced by young people and their families. More than half of the sample of both AYAs and parents reported financial difficulties during cancer treatment, and two-thirds of AYAs and a third of parents reported it was important to receive income support during treatment. It is notable that over two thirds of AYAs and parent carers who reported needing financial support described difficulty accessing it during treatment, with bureaucratic challenges commonly experienced around accessing government financial support. While the financial impacts of cancer have been previously shown for cohorts of older adults and younger children, few studies have articulated the particular challenges for 15-25 year olds. To our knowledge, this is the first study to outline the extent of financial impact on parent carers of AYAs with cancer.

Financial issues and income support remained pertinent for many AYAs after treatment, with almost half of those who were off treatment reporting they were either only

partially or not back on track with work. Given survival rates from cancer for AYAs are quite high (Australian Institute of Health and Welfare, 2011), and the potential of protracted chronic health effects, there appears to be a need for ongoing income support for at least some. This is reflective of the adult cancer literature in which the duration for which income support is required is increasingly appreciated (D'Agostino et al., 2011; Paalman et al., 2016; Wakefield et al., 2013; Yabroff et al., 2016).

A notable finding of our study is that almost three quarters of AYAs were living with their parents at the time they completed the survey. We are unable to identify whether, and if so, what proportion of young people moved home following the diagnosis of cancer or specifically due to financial challenges. Our overall proportion of 15-24 year olds (79%) living at home is considerably higher than the Australian average of 65.7%. More specifically, a higher proportion of young people aged 25 years and older lived at home in our sample (21%) than in the Australian population (12%) (The National Housing Supply Council, 2013). It may be anticipated that AYAs with cancer would choose to live with family during and after cancer treatment for physical and emotional support. That almost two thirds of AYAs who reported financial difficulties were living with their parents suggests that AYAs may also move home or continue to live at home for financial support. Regression data indicates that living in the family home is more likely to provide a protective effect on AYA financial issues, which potentially supports the notion that that financial impacts may be a contributing factor to the high numbers of AYAs living with their families.

Despite Australia's notionally universal healthcare system, surprisingly, almost one half of AYAs (44%) and almost one third of parents (29%) reported financial challenges due to direct costs of medical expenses. These results may reflect the growing trend of increased medical expenses, higher medical and pharmaceutical co-payments (Gordon et al., 2017) and the extent of gap payments for both public and private patients that have been reported for

Australian adults with cancer (Gordon et al., 2017). Further research is required to fully comprehend the extent of direct medical costs associated with cancer that are borne by Australian AYAs and their families. High indirect costs of transportation, including car parking, were a substantial financial burden for many parents, consistent with previous research of families of children and adults with cancer (Brooks, Wilson, & Amir, 2011; Cohn et al., 2003; Heath et al., 2006; Stommel, Given, & Given, 1993). Together with the costs of accommodation, this likely explains why a regional/rural location was associated with parent financial issues, and is particularly relevant for Australia given the large distances that many families have to travel for cancer treatment (Daniel et al., 2013; Fluchel et al., 2014; McGrath et al., 1999). While families from regional/rural areas in Australia can access special initiatives to alleviate travel costs such as sponsored accommodation and travel assistance, it is not known to what extent these schemes were utilised by this cohort. What is known is that family accommodation support is heavily utilized and not always available (Cohn et al., 2003; Daniel et al., 2013). Finally, more than a quarter of parents reported needing income support both during and after treatment. During treatment, income support was significantly associated with a blood cancer diagnosis. Younger age at diagnosis, paediatric treatment setting and prolonged admission were also significant and are factors that likely reflect the intensive treatment of blood cancers such as leukaemia in younger populations. Many of these same factors were associated with the need for ongoing income support. Consistent with the paediatric literature (Daniel et al., 2013; Fluchel et al., 2014), this reinforces how long income support may be required for some AYA carers.

Our data suggest that AYAs with cancer and their families are multiply disadvantaged financially. They experience significant financial expenses due to cancer, which for many families is compounded by loss of income of the AYA and a parent. In addition to many AYAs being ineligible for financial assistance, most parents in this cohort were also

ineligible for any significant government assistance as carers. This raises questions about the appropriateness of current eligibility criteria for income support for AYAs with cancer as well as for their parent carers. There was confusion about which of the different income support schemes AYAs with cancer were eligible. Furthermore, many of those deemed eligible were placed on schemes that appeared inappropriate given their health circumstances. These data suggest a more systematic approach is required for the assessment of the financial needs of AYAs with cancer that have diverse and changing health needs. This would ideally recognise the extent and duration of health needs, the high costs of cancer care, the availability of family carers, and for many, a significant delay in their ability to return to their former level of study or work. A similar approach could be employed for the financial assessment of parent carers.

There are several limitations of this study. Being cross sectional, it precludes interpretation of causality. A longitudinal repeated measures design would enable more dynamic assessment of the financial impacts of cancer over time. Families with limited English literacy, those with cognitive impacts, and those too unwell to participate were excluded. These groups would be expected to experience financial issues, suggesting that the data presented here are conservative, and may well be an underestimate of AYAs and their families who are financially affected by cancer. While the relatively low response rate means that caution must be exercised when extrapolating findings to other populations, especially to those with different systems of health financing, insurance and financial support, this response rate is consistent with other studies of this age group (Clinton-McHarg, Carey, Sanson-Fisher, & Tracey, 2011; Drew, Duncan, & Sawyer, 2010). Our study did not comprehensively explore the extent of out-of-pocket medical expenses, the impact of private health insurance, household income, nor the role of charitable organisations in lessening the financial burden for AYAs and their families. Further research is required to fully appreciate

the financial impact of cancer on Australian AYA and their families and how this might best be alleviated.

In conclusion, this study has identified that cancer in AYAs is a cause of significant financial impact in both young people themselves and their parent carers, not only during treatment but well into survivorship. A key finding is the extent to which 15-25 year olds AYAs rely on their parents for financial support. These findings suggest that, like the Psychosocial Standards of Care outlined for pediatric cancer (Pelletier & Bona, 2015), policy around financial support for AYAs with cancer must also extend to address the financial impacts on families in order to alleviate the substantial financial burdens that accrue from the AYA cancer experience. Any review of Government policy related to income support, should consider the introduction of a medium term disability component or extended sickness benefit for those people with complex illnesses, including AYAs with cancer and their caregivers.

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Table 1- AYA Socio-demographic and clinical characteristics (N= 196^a)

Characteristic	Number (% where relevant)		
Age (years) at survey mean (SD), range	21.6 (3.1), 15-27		
Dichotomized [^]			
15-24 years	150 (79%)		
25+ years	41 (21%)		
Age (years) at diagnosis (n=194) mean (SD), range	19.9 (3.2), 15-26		
Age group at diagnosis (n=194)			
15-19 years	87 (45%)		
20-25 years	107 (55%)		
Time since diagnosis-months (n=183) Mean (SD), range	19.06 (8.18), 6-33		
Treatment setting			
Adult	168 (86%)		
Pediatric	27 (14%)		
Cancer type (n=193)			
Malignant hematological cancer	60 (31%)		
Hodgkin's Lymphoma	48 (25%)		
Sarcoma	29 (15%)		
Brain tumor	17 (9%)		
Germ cell tumor	14 (7%)		
Melanoma	7 (4%)		
Thyroid tumor	5 (3%)		
Other	13 (7%)		
Sex			
Male	99 (51%)		
Female	97 (49%)		
Employment/education status at survey ^b	Full-time	Part-time	
High school student	29	6	(18%)
Tertiary student	47	15	(32%)
Working	48	44	(47%)
Unemployed	21	-	(11%)
Homemaker/family caregiver	2	-	(1%)
Other	10	-	(5%)
Geographic location (n=193)			
Major metropolitan city	123 (64%)		
Regional city	44 (23%)		
Rural area	26 (13%)		
Resides with (n=230) ^b			
Parents	141 (72%)		
Partner	23 (12%)		
Other family	20 (10%)		
Boyfriend/girlfriend	18 (9%)		
Friends	15 (8%)		
Other	13 (7%)		

^a Percentages use total number of responses as denominator, otherwise n=196 is used as the denominator

^b Totals are for number of responses due to a 'tick all that apply' question type

[^] Dichotomized for comparison to the National Housing Supply Council data (2013)

Table 2. Parent socio-demographic characteristics (N= 204^a)

Characteristic	Number (%) of parents	
Relationship to AYA with cancer (n=203)		
Mother	180 (89%)	
Father	19 (9%)	
Stepmother	1 (0.5%)	
Stepfather	2 (1%)	
Female guardian	1 (0.5%)	
Country of birth (n=200)		
Australia	138 (69%)	
Other	62 (31%)	
Education level (n=201)		
Left school before completing Year 10	14 (7%)	
Year 10 or equivalent	31 (15%)	
Year 12 or equivalent	35 (17%)	
Certificate or diploma	59 (29%)	
Bachelor or higher degree	62 (31%)	
Employment/education status at survey	Full-time	Part-time
Working	78	65 (70%)
Unemployed	4	- (2%)
Homemaker/family caregiver	37	7 (22%)
Other	9	4 (6%)
Geographic location (n=200)		
Major metropolitan city	119 (60%)	
Regional city	49 (25%)	
Rural area	28 (14%)	
Remote or very remote area	4 (2%)	
Number of children in family (n=198)		
Mean (SD), range	2.76 (1.13), 1-7	
Relationship Status (n=200)		
No partner	23 (12%)	
Defacto partner	12 (6%)	
Married (first marriage)	124 (62%)	
Separated	7 (4%)	
Divorced	16 (8%)	
Remarried	18 (9%)	
Who do you live with most of the time (n=294)^b		
Child/children	154 (75%)	
Child/children	2 (1%)	
Extended family	127 (62%)	
Partner/Defacto/Spouse	7 (3%)	
Alone	4 (2%)	
Other		
Number of children living at home (n=129)		
Mean (SD), range	2.12 (1.00), 1-7	

^a Percentages use total number of responses as denominator, otherwise n=204 is used as the denominator

^bTotals are for number of responses due to a 'tick all that apply' question type

Table 3. Logistic regression analysis of socio-demographic and clinical setting and treatment variables on financial impact of cancer on AYAs and parents

Variables	AYAs			Parents			
	Odds ratio	CI	p		Odds ratio	CI	p
Socio-demographic variables							
Gender male (female, reference)	0.61	0.33, 1.11	0.11		1.24	0.61, 2.55	0.56
Geography regional/rural (metropolitan, reference)	1.06	0.57, 2.00	0.85		2.03	1.13, 3.71	0.02
Living arrangement family home (living outside family home, reference)	0.5	0.25, 0.98	0.04		2.90	1.0, 8.5	0.05
Employment status unemployed (employed, reference)	2.09	0.87, 5.06	0.10				
Education level				Completed Year 10 or equivalent	0.78	0.11, 2.08	0.32
				Completed Year 12 or equivalent	0.34	0.08, 1.45	0.14
				Certificate or Diploma	0.53	0.13, 2.14	0.37
				Bachelor or higher degree	0.31	0.78, 1.24	0.10
				<Year 10 (reference)			
Clinical setting and treatment variables							
Age at diagnosis 20-25 years (15-19 years, reference)	1.98	1.06, 3.67	0.03	Age at diagnosis [#] 15-19 years 20-25 years (reference)	2.46	1.18, 5.12	0.02
Length of hospital stay long stay (short stay, reference)	1.32	0.71, 2.43	0.38		2.04	1.12, 3.7	0.02
On/off treatment on treatment (off treatment, reference)	1.05	0.48, 2.31	0.91		1.58	0.8, 3.11	0.19
Treatment setting (adult versus pediatric) adult (pediatric, reference)	0.89	0.34, 2.3	0.81		0.63	0.29, 1.4	0.24
Cancer type (blood versus other) blood cancer (other, reference)	0.99	0.54, 1.82	0.98		1.96	0.94, 4.1	0.07

*Bold values used to highlight a p value of less than 0.05 (95% Confidence intervals [CI]). [#] Parent age at diagnosis has older age group as reference

Table 4- AYA and Parent logistic regression –need for income support *during* treatment

Variables	AYA			Parent			
	Odds ratio	CI	p		Odds ratio	CI	p
Socio-demographic variables							
Gender male (female, reference)	0.83	0.47, 1.49	0.54		1.17	0.56, 2.42	0.68
Geography regional/rural (metropolitan, reference)	1.34	0.73, 2.48	0.34		2.40	1.32, 4.37	<0.01
Living arrangement family home (living outside family home, reference)	0.67	0.35, 1.29	0.23		3.4	0.91, 12.42	0.07
Employment status unemployed (employed, reference)	3.29	1.28, 8.45	0.01				
Education level				Completed Year 10 or equivalent	0.62	0.17, 2.20	0.46
				Completed Year 12 or equivalent	0.67	0.19, 2.34	0.53
				Certificate or Diploma	0.58	0.18, 1.90	0.37
				Bachelor or higher degree	0.20	0.06, 0.69	0.01
				<Year 10 (reference)			
Clinical setting and treatment variables							
Age at diagnosis 20-25 years (15-19 years, reference)	2.22	1.23, 4.01	<0.01	Age of AYA at diagnosis 15-19 years [#] (20-25 years, reference)	4.9	2.2, 10.96	<0.001
Length of hospital stay long stay (short stay, reference)	1.24	0.69, 2.23	0.48		3.8	2.08, 7.11	<0.001
On/off treatment on treatment (off treatment, reference)	1.06	0.50, 2.23	0.88		1.27	0.66, 2.45	0.48
Treatment setting (adult versus paediatric) adult (paediatric, reference)	1.19	0.51, 2.78	0.69		7.8	3.3, 18.42	<0.001
Cancer type (blood versus other) blood cancer (other, reference)	1.13	0.63, 2.03	0.68		2.3	1.06, 4.97	0.04

*Bold values used to highlight a p value of less than 0.05 (95% Confidence intervals [CI]). [#] Parent age at diagnosis has older age group as reference

Table 5- AYA and Parent logistic regression-need for income support *after* treatment

Variable	AYA			Parent			
	Odds ratio	CI	p		Odds ratio	CI	p
Socio-demographic variables							
	0.64	0.36, 1.14	0.13		0.89	0.38, 2.07	0.79
Socio-demographic variables	1.34	0.74, 2.44	0.34		2.31	1.18, 4.5	0.01
Living arrangement family home (living outside family home, reference)	0.79	0.42, 1.49	0.47		1.54	0.41, 5.85	0.53
Employment status unemployed (employed, reference)	3.22	1.40, 7.44	0.01				
Clinical setting and treatment variables							
Age at diagnosis 20-25 years (15-19 years, reference)	1.14	0.64, 2.04	0.65	Age at diagnosis 15-19 years [#] (20-25 years, reference)	3.97	1.53, 10.28	<0.01
Length of hospital stay long stay (short stay, reference)	1.50	0.84, 2.68	0.17		2.30	1.18, 4.51	0.02
Treatment setting (adult versus paediatric) adult (paediatric, reference)	1.17	0.50, 2.73	0.72		3.31	1.52, 7.2	<0.01
Cancer type (blood versus other) blood cancer (other, reference)	0.60	0.33, 1.06	0.08		1.50	0.63, 3.61	0.36

*Bold values used to highlight a p value of less than 0.05 (95% Confidence intervals [CI]). [#] Parent age at diagnosis has older age group as reference