



Developmentally appropriate care for adolescents and young adults with cancer: how well is Australia doing?

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Abstract

Purpose Developmentally appropriate care underpins quality cancer treatment. This study aimed to describe how well Australian cancer services deliver patient-focussed, developmentally appropriate care to adolescents and young adults (AYAs) with cancer.

Methods In a national, cross sectional study, 196 AYAs with cancer aged between 15 and 25 years at diagnosis reported their general experiences of the cancer care team (Cancer Needs Questionnaire), access to age-appropriate treatment environments (Cancer Needs Questionnaire) and frequency of psychosocial assessment (Adolescent Friendly Hospital Survey).

Results Very positive responses were reported around engagement and communication with staff who were reported as approachable, friendly and trustworthy; 11 of the 14 items were positively rated by over 90% of respondents. In contrast, over 70% of AYAs expressed unmet need around their physical and social environments, whether in relation to the opportunity to be nursed in wards designed for AYAs, spend time with other young people with cancer, or talk to young people their own age; less than a third reported their needs had been met on the majority of these items. The frequency that specific psychosocial assessment domains were discussed was highly variable; responses suggested that AYAs were less commonly questioned about overtly sensitive topics. AYAs who experienced private consultations with health care providers (41%) were significantly more likely to experience thorough psychosocial assessment.

Conclusion Australian cancer services are generally communicating well with AYAs. There is room for improvement around more developmentally specific aspects of healthcare quality, such as psychosocial assessment, and around treatment environments that promote greater social interaction between AYAs.

Keywords Adolescents · Quality · Risk assessment · Confidentiality · Patient-reported outcomes · Patient experience · Physical environment · Health reform

Introduction

Healthcare systems are challenged to deliver quality healthcare to adolescents and young adults (AYAs) with complex health conditions [1]. For cancer services, part of the challenge is embedded within the complex spectrum of cancer biology during these years which results in a wide diversity of cancer types. This is particularly challenging for specialist cancer services which have been able to focus technical expertise around either childhood or adult cancers, rather than those that affect AYAs [2]. The multiple biological, social and educational transitions that characterise this developmental period raise additional challenges in delivering healthcare to AYAs with cancer, and their families [1–4]. Efforts to promote AYA cancer service reform, drive research and advance clinical training in the UK, North America and Australia are based on the need to respond to these complexities by improving

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both the quality of cancer care and the quality of care that is provided to the young person with cancer [2, 5–8].

Some AYA needs are universally experienced but others are more developmentally distinct or significant during these years. Thus, for AYAs with cancer, developmentally appropriate services are required to address mental health needs, consider threats to fertility and promote re-engagement with education and training given the particular significance of these issues for this age group [9, 10]. The importance of meeting patient-reported needs and assuring positive care experiences are increasingly appreciated as unmet health care needs are associated with poorer emotional wellbeing and distress [10–12], reduced health-related quality of life [13] and less resiliency [12]. Just like clinical needs, aspects of patient experience are especially pertinent for AYAs with cancer. For example, Furness and colleagues recently reported that 16–24 year olds with cancer in the UK were less involved in healthcare discussions than they would have liked when compared to older patients [14]. While a physical environment that promotes interactions with same-aged peers and trained clinical staff has been consistently identified to contribute to a positive experience of care, few studies describe AYAs' access to developmentally appropriate facilities [15]. For example, Furness and colleagues noted that a limitation of their study was their inability to report on the appropriateness of treatment environments for AYAs with cancer [14].

Emanating from the World Health Organization, the language of 'adolescent friendly health care' encapsulates quality health care that addresses manifest health issues (e.g. the treatment of cancer) while ensuring that developmentally significant health issues are also addressed (e.g. psychosocial wellbeing, health literacy) and emerging or future health risks are minimised (e.g. contraception, tobacco control) [3, 16, 17]. Sawyer and colleagues recently developed a conceptual framework to shape the delivery of quality healthcare to adolescents within a hospital environment that integrates concepts of patient- and family-centred care, experience of care and evidence-informed care [18]. This developmentally informed framework includes key experience of care indicators such as how welcome young people feel in the hospital, how involved they are in decision-making and whether they consider care to be delivered in an age-appropriate environment. Further quality indicators relate to evidence-informed AYA care, such as the extent that psychosocial assessment is undertaken, that time alone with clinicians is provided, that there are discussions around self-management and efforts to promote social support.

Using data from a national Australian survey of AYAs with cancer and their parent carers [19], we have previously reported the extent that AYAs and their parents have their needs met around clinical services such as pain management, mental health care, and support to re-engage with education and employment [10]. We have also reported the extent to which

quality information is provided to AYAs and parents, and the association between patient activation and reduced emotional distress [20]. In this paper, we report three measures of experience of care and evidence-informed care, including the physical treatment environment, with the goal of identifying how well Australian AYA cancer services are providing quality care to adolescents with cancer. Given evidence for different experiences by sex, age and treatment setting (adult versus paediatric) [10, 20], we were also interested in how these factors influence the delivery of developmentally appropriate care.

Methods

The Youth Friendly Cancer Care project is a multi-stage study which has the broad objective of influencing AYA cancer service development. The first stage was a qualitative analysis of interviews with 60 AYAs and 60 carers from three Australian states which informed the choice of measures that were included in a quantitative survey. The second stage was a national survey of 196 AYAs (the focus of this paper) and 204 parent carers. The study methods are described briefly below as a detailed description has been previously published [19].

Participants

Eligible patients were 15–25 years old at the time of cancer diagnosis, and between 6 and 24 months from diagnosis (of a new cancer, a recurrence or relapse of a previous cancer) at the time of the study. Exclusion criteria were the inability to complete the survey, and stage 1 and 2 melanoma (as these are generally not managed by cancer services).

Recruitment

The research team approached 21 public hospitals which provide the majority of AYA cancer treatment across all states of Australia, and CanTeen, a national charitable AYA cancer organisation. Seventeen of the 21 clinical services (12 adult, 5 paediatric) agreed to participate, together with CanTeen. At each site, ethics and governance approval was obtained for clinical liaison personnel to identify potentially eligible AYAs (and parent carers) from clinical or Health Information Services databases, who were then sent a survey package. Packages were sent to parents of AYAs less than 18 years of age, who were requested to pass the survey on to their child if they consented.

Measures

For the purpose of this paper, we report data from three of the survey measures which set out to broadly identify the AYA

experience of care in relation to the cancer care team and the hospital environment together with assessment of the quality of care provided to the AYA.

Experience of care: the cancer care team

The Cancer Needs Questionnaire-Young Person (CNQ-YP) was used to assess AYAs' experience of the cancer care team [21]. Twelve items were taken directly from the CNQ-YP–Treatment Environment and Care domain together with an additional two items to expand questions around the care team ('were people I could trust to take care of my health' and 'included my family in discussions and decision making the way I want (ed) them to be included'). Response options ranged from *Never*, *Almost never*, *Sometimes*, *Often*, and *Almost always*. Each of these was dichotomised to no (*Never*, *Almost never*) and yes (*Sometimes*, *Often*, *Almost always*) for further analysis. The Cronbach alpha for this measure was 0.89, as compared to the original measure of 0.98 [21].

Experience of care: developmentally appropriate treatment environment

Eight items were used to assess AYAs' experience of the treatment environment. Five questions were sourced from the CNQ-YP questionnaire–Information and Activities domain. Four of these items were used verbatim and one was modified slightly. Three additional questions explored young people's access to adolescent-specific rooms or wards, their access to quiet rooms for relaxation and flexibility around scheduling appointments. Consistent with previously reported analyses [9, 10], response options were modified to a two-component question. These firstly identified whether or not the AYA had access to each specific element of the treatment environment (*Yes—I had access to this* or *No—I did not have access to this*) and then identified whether or not this was helpful or would have been helpful (*Yes—this was/would have been helpful for me* or *No—this was not/would not have been helpful for me*). As previously reported [10], unmet need was defined as those who did not have access to the service but indicated it would have been helpful. The Cronbach alpha for this measure was 0.76, compared to 0.83 in the original measure [21].

Quality of care: psychosocial assessment

The psychosocial assessment domain of the Adolescent Friendly Hospital Survey was used to measure whether adolescents had been questioned about the critical domains that underpin quality care delivery to AYAs (as distinct to their experience of care or the specific treatment of their cancer) [22]. These 11 items assess whether the healthcare team has taken a thorough psychosocial history through discussion of

their home life, education or employment, friends and activities, as well as whether anyone in the care team had asked about drug and alcohol use, sexual health and mental health. Response options were, 'Yes, in the last 6-12 months', 'Yes, more than 6 months ago', and 'No, never'. The two positive responses were combined to yield a dichotomised yes/no response. The Cronbach alpha for this measure was 0.87.

Statistical analysis

Descriptive statistics were used to report the demographic and clinical characteristics of the AYA cohort. Chi-square and two-sided Fisher's exact tests were used to investigate the association between the variables for the three measures and sex, age at diagnosis, treatment centre (adult versus paediatric).

Results

Demographics

The demographic profile of the 196 AYAs has been previously detailed [19]. The mean age was 19.6 at diagnosis and 21.6 at the time of survey. The mean time since diagnosis was 19.85 (SD 3.17) months. Approximately half were male (51%) and working (47%), and 64% lived in metropolitan areas. Malignant haematological cancers (31%) and Hodgkin's lymphoma (25%) constituted over half of the diagnoses. The majority (86%) were treated in an adult setting, and 81% had finished active treatment.

Experience of care: the cancer care team

The majority of AYAs (90% or greater) reported positive responses for 11 of the 14 experience of care items which related to the quality of communication and general interactions with the cancer care team, as shown in Fig. 1. The most highly endorsed of these experience of care items related to staff being friendly and respectful, communicating in ways that AYAs understood, being supportive of AYAs asking questions, and engaging families in discussions and decisions as AYAs wished.

Table 1 presents these data by sex, age at diagnosis and treatment centre. Older AYAs (aged 20–25 years at diagnosis) were more likely to report that health staff let them make decisions about their treatment compared to younger AYAs ($\chi^2 = 8.32$, $p = 0.004$), as were AYAs treated in adult rather than paediatric settings ($\chi^2 = 5.34$, $p = 0.02$). Older AYAs were also more likely to report that health staff included their family in discussions and decision-making the way they wanted them to be included (Fisher's exact test, $p = 0.006$).

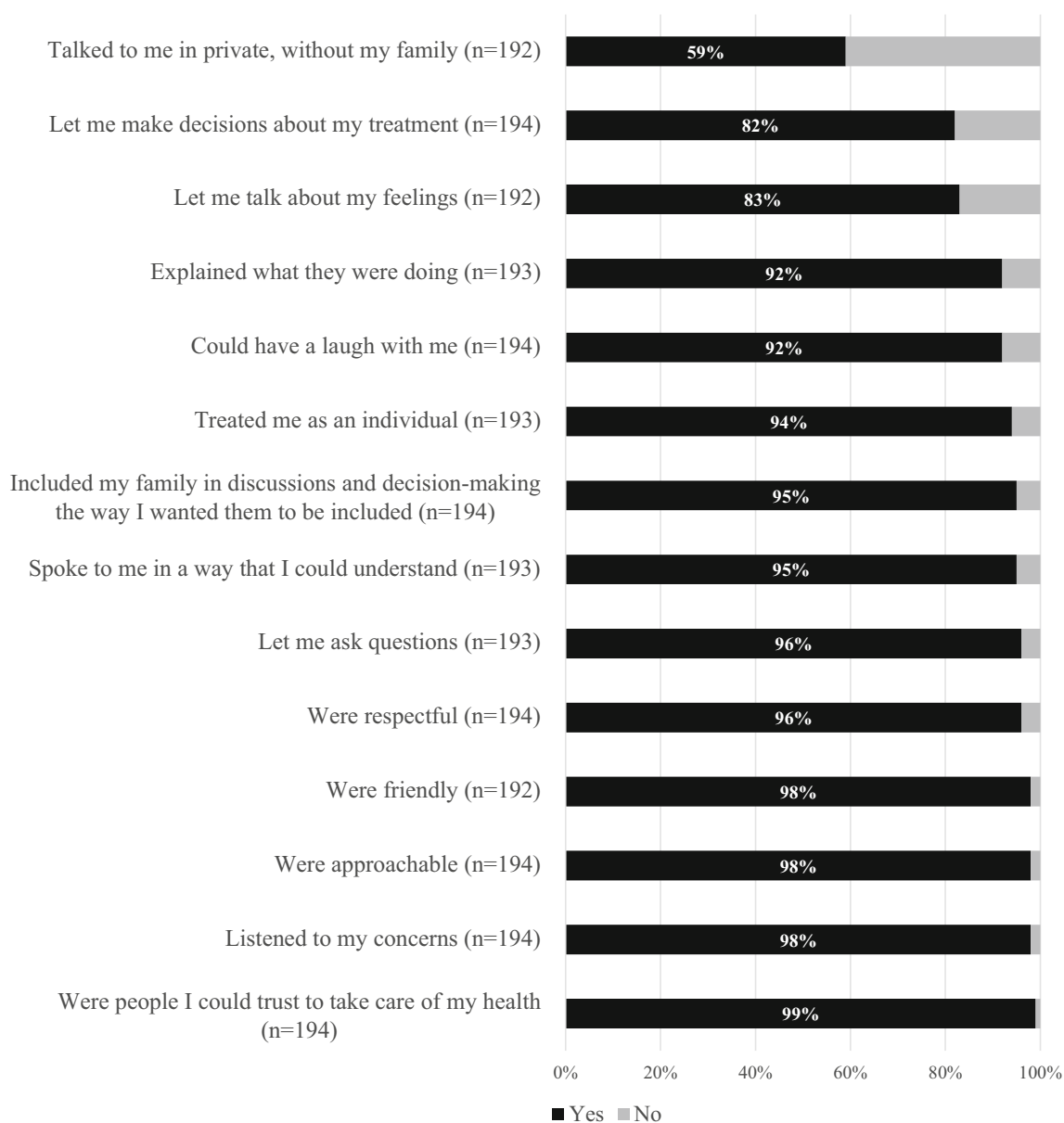


Fig. 1 Proportion of AYAs who reported positive responses (black) around aspects of engagement and communication with their cancer care team

Experience of care: age-appropriate treatment environment

Responses were less positive for the age-appropriate treatment environment measure. The most frequently reported unmet needs were for AYA-specific wards (80%), spending time with AYAs their own age (75%), having flexibility around scheduling medical appointments (74%), and having access to AYA-specific recreational activities and spaces (71% and 70%, respectively). Sixty-three percent reported not having access to developmentally appropriate information about cancer and its treatment and 49% reported not having access to a quiet room away from wards. More than three quarters of participants reported at last one unmet need across the 8 items.

Females reported higher unmet needs for spending time with people their own age ($\chi^2 = 16.4$, $p \geq 0.001$), meeting other adolescents who had been through a similar experience ($\chi^2 = 10.92$, $p = 0.001$), access to age-appropriate leisure spaces ($\chi^2 = 9.29$, $p = 0.002$), access to age-appropriate activities ($\chi^2 = 5.30$, $p = 0.02$), access to a quiet room ($\chi^2 = 4.43$, $p = 0.04$) and age-appropriate cancer information ($\chi^2 = 13.92$, $p > 0.001$), as shown in Table 2. Older AYAs reported higher unmet need for access to rooms or wards specifically designed for AYAs ($\chi^2 = 4.15$, $p = 0.04$). Those treated in the adult sector were twice as likely as those in the paediatric sector to have an unmet need for access to rooms specifically designed for AYAs ($\chi^2 = 3.92$, $p = 0.048$) and for meeting people their own age who had been through a similar experience ($\chi^2 = 6.41$, $p = 0.01$).

Table 1 Proportion of positive responses reported by AYAs about their cancer care team, by sex (male, female), age at diagnosis (15–19 years, 20–25 years) and treatment centre (paediatric, adult) ($n=196^1$)

| Item | Sex | | | Age at diagnosis | | | Treatment centre | | |
|--|--------|----------|----------------|------------------|---------------|----------------|------------------|---------|----------------|
| | % male | % female | <i>p</i> value | % 15–19 years | % 20–25 years | <i>p</i> value | % paediatric | % adult | <i>p</i> value |
| Listened to my concerns | 99 | 97 | 0.29 | 98 | 98 | 0.85 | 100 | 98 | 0.54 |
| Were people I could trust to take of my health | 98 | 100 | 0.16 | 99 | 99 | 0.89 | 100 | 99 | 0.74 |
| Treated me as an individual | 96 | 93 | 0.31 | 97 | 92 | 0.21 | 96 | 94 | 0.53 |
| Were respectful | 99 | 98 | 0.23 | 98 | 99 | 0.89 | 100 | 98 | 0.60 |
| Were approachable | 98 | 95 | 0.54 | 97 | 96 | 0.54 | 100 | 96 | 0.64 |
| Were friendly | 97 | 99 | 0.32 | 99 | 97 | 0.62 | 100 | 98 | 0.54 |
| Could have a laugh with me | 93 | 92 | 0.73 | 91 | 93 | 0.52 | 85 | 93 | 0.23 |
| Explained what they were doing | 92 | 93 | 0.87 | 91 | 93 | 0.53 | 96 | 92 | 0.7 |
| Spoke to me in a way that I could understand | 98 | 91 | 0.053 | 97 | 93 | 0.35 | 96 | 95 | 0.58 |
| Let me talk about my feelings | 87 | 80 | 0.22 | 81 | 85 | 0.56 | 78 | 84 | 0.41 |
| Let me ask questions | 98 | 94 | 0.14 | 95 | 96 | 0.80 | 100 | 95 | 0.60 |
| Let me make decisions about my treatment | 84 | 81 | 0.61 | 74 | 90 | 0.004 | 67 | 85 | 0.02 |
| Talked to me in private, without my family | 61 | 57 | 0.60 | 53 | 64 | 0.13 | 54 | 60 | 0.51 |
| Included my family in discussions and decision-making the way I wanted them to be included | 94 | 96 | 0.56 | 90 | 99 | 0.006 | 93 | 95 | 0.63 |

¹ *n* varied from 190 to 194 due to missing data

p values in bold indicate statistical significance

Quality of care: psychosocial assessment

Over 80% of AYAs reported that health professionals had discussed the following topics in the last year: how they were

managing emotionally (92%), education and employment (92%), home and family life (91%) and healthy habits such as exercise (91%) and peer relationships (87%). As shown in Fig. 2, a considerable proportion reported not having

Table 2 Proportion of AYAs ($n=196^1$) who reported met need for age-appropriate treatment environment items, by sex (male, female), age at diagnosis (15–19 years, 20–25 years) and treatment centre (paediatric, adult)

| Item | Sex | | | Age at diagnosis | | | Treatment centre | | |
|---|--------|----------|------------------|------------------|---------------|----------------|------------------|---------|----------------|
| | % male | % female | <i>p</i> value | % 15–19 years | % 20–25 years | <i>p</i> value | % paediatric | % adult | <i>p</i> value |
| Spend time with people my own age | 39 | 10 | <0.001 | 23 | 26 | 0.71 | 42 | 21 | 0.051 |
| Talk to people my age who had been through a similar experience | 44 | 18 | 0.001 | 34 | 29 | 0.51 | 55 | 27 | 0.011 |
| Access leisure spaces appropriate for my age group | 42 | 18 | 0.002 | 31 | 29 | 0.87 | 43 | 27 | 0.15 |
| Access leisure activities appropriate for my age group | 38 | 20 | 0.02 | 33 | 25 | 0.30 | 41 | 26 | 0.17 |
| Access hospital patient rooms or wards specifically designed for AYAs | 25 | 15 | 0.12 | 28 | 14 | 0.042 | 37 | 17 | 0.048 |
| Access quiet space away from patient rooms/wards for relaxation | 59 | 41 | 0.04 | 51 | 51 | 0.98 | 55 | 50 | 0.67 |
| Access information about cancer, its treatments and wellbeing that was specifically designed for my age group | 77 | 49 | <0.001 | 63 | 63 | 0.98 | 64 | 63 | 0.93 |
| Flexibility in scheduling medical appointments to help fit in around other aspects of my life | 76 | 73 | 0.61 | 73 | 76 | 0.67 | 70 | 75 | 0.57 |

¹ *n* varied from 138 to 149 due to missing data

p values in bold indicate statistical significance

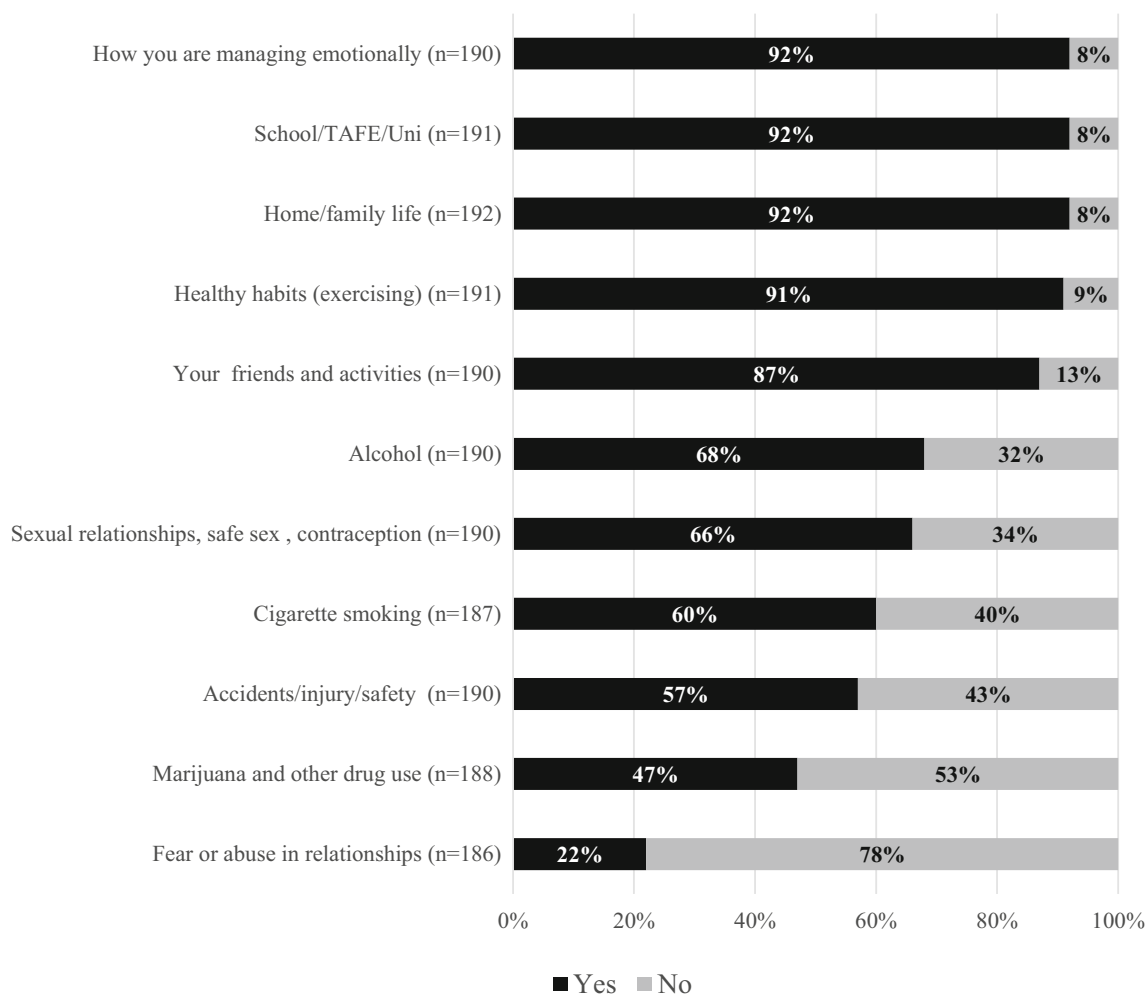


Fig. 2 Proportion of AYAs who reported evidence of psychosocial assessment (in black) within the past 12 months

Table 3 Proportion of AYAs who reported psychosocial assessment within the past 12 months, by sex (male, female), age at diagnosis (15–19 years, 20–25 years) and treatment centre (paediatric, adult). TAFE refers to Australia’s system of Tertiary and Further Education (n = 196¹)

| Item | Sex | | | Age at diagnosis | | | Treatment centre | | |
|---|--------|----------|-------------|------------------|---------------|--------------|------------------|---------|-------------|
| | % male | % female | p value | % 15–19 years | % 20–25 years | p value | % paediatric | % adult | p value |
| Home, family life | 93 | 91 | 0.72 | 91 | 93 | 0.51 | 96 | 92 | 0.36 |
| School, TAFE, university | 92 | 91 | 0.95 | 93 | 90 | 0.50 | 93 | 91 | 0.60 |
| Healthy habits (e.g. exercising) | 93 | 89 | 0.41 | 92 | 90 | 0.71 | 96 | 90 | 0.27 |
| Friends and activities | 91 | 83 | 0.12 | 92 | 82 | 0.06 | 100 | 85 | 0.03 |
| Accidents, injury, safety | 65 | 48 | 0.02 | 58 | 55 | 0.75 | 68 | 55 | 0.22 |
| Cigarette smoking | 68 | 52 | 0.03 | 56 | 62 | 0.45 | 46 | 62 | 0.13 |
| Alcohol | 75 | 60 | 0.03 | 69 | 67 | 0.72 | 54 | 70 | 0.10 |
| Marijuana and other drug use | 54 | 41 | 0.08 | 49 | 46 | 0.71 | 48 | 47 | 0.92 |
| Sexual health (e.g. relationships, safe sex, contraception) | 64 | 64 | 0.54 | 56 | 76 | 0.004 | 46 | 70 | 0.02 |
| Emotional wellbeing | 91 | 94 | 0.44 | 95 | 89 | 0.12 | 96 | 91 | 0.34 |
| Fear or abuse in relationships | 23 | 21 | 0.71 | 19 | 25 | 0.37 | 28 | 21 | 0.30 |

¹ n varied from 184 to 192 due to missing data

p values in bold indicate statistical significance

Table 4 Likelihood of psychosocial assessment in the past 12 months according to whether clinicians were reported to have had a private discussion with the AYA ($n = 196^1$) without family present

| Item | Number (n) that reported discussion of item in the past 12 months | Had private discussion | | |
|---|---|------------------------|--------|------------------|
| | | Yes (%) | No (%) | p value |
| Home, family life ¹ | 177 | 61 | 39 | 0.29 |
| School, TAFE, university | 175 | 62 | 38 | 0.004 |
| Healthy habits (e.g. exercising) | 174 | 61 | 39 | 0.11 |
| Friends and activities | 165 | 62 | 38 | 0.04 |
| Accidents, injuries, safety | 108 | 67 | 33 | 0.02 |
| Cigarette smoking | 112 | 68 | 32 | 0.002 |
| Alcohol | 129 | 65 | 35 | 0.01 |
| Marijuana and other drug use | 89 | 70 | 30 | 0.002 |
| Sexual health (e.g. relationships, safe sex, contraception) | 126 | 65 | 35 | 0.02 |
| Emotional wellbeing | 175 | 60 | 40 | 0.64 |
| Fear or abuse in relationships | 41 | 10 | 90 | <0.001 |

¹ Number varies slightly for each item due to missing data
 p values in bold are statistically significant

discussed behaviours or risks in the last year, such as substance use (responses ranged from 32% for alcohol to 53% for other drugs) and safe sex including contraception (34%). The majority reported not having discussed fear or abuse in relationships (78%).

Males were more likely to report that health professionals had preventively oriented discussions about accidents and injury ($\chi^2 = 5.91$, $p = 0.02$), alcohol ($\chi^2 = 4.91$, $p = 0.03$) and smoking ($\chi^2 = 5.02$, $p = 0.03$) than females, as shown in Table 3. Younger AYAs were significantly less likely to report having discussed sexual health, including contraception, than older AYAs ($\chi^2 = 8.42$, $p = 0.004$). AYAs treated in adult settings were significantly more likely to report having discussed sexual health than those in paediatric settings ($\chi^2 = 5.71$, $p = 0.02$). In contrast, AYAs treated in adult settings were less likely than those treated in paediatric settings to report having discussed peer relations and friendships (Fisher's exact test, $p = 0.03$). The likelihood of a psychosocial history having been taken was significantly greater when AYAs reported consulting privately with a clinician without their family present, as shown in Table 4.

Discussion

Internationally, health systems are at various stages of responding to the complex challenge of providing developmentally appropriate care to AYAs with cancer. In Australia, significant government investment to improve the quality of care delivered to AYAs with cancer has been undertaken over the past decade [5]. The results reported here provide confidence that Australian cancer services are doing well in a number of important domains of patient experience. At the same time, there is distinct room for improvement around other

important aspects of quality care of AYAs, particularly around the appropriateness of physical and social environments, and the quality of psychosocial assessment.

Very positive responses were reported by AYAs around the general attributes of staff who were reported to be highly approachable, friendly and trustworthy. Indeed, that 11 of the 14 items were positively rated by over 90% of respondents in this national survey of 15–25 year olds with cancer is a remarkable endorsement. Excellent communication from treating teams is appreciated to be a critical component of high-quality cancer care, strongly affecting patient perceptions of quality of care [23]. It is noteworthy that a recent systematic review of experience of care in AYAs with cancer identified that the quality of clinician's listening skills, sensitivity, empathy and trust were key facilitators of information exchange in this age group [15]. Despite this, surprisingly few studies are available for benchmarking the patient experience of AYAs with cancer. The majority of studies have utilised qualitative methods which precludes direct comparison. Those using quantitative methods have either reported patient rankings of the importance of different aspects of patient experience or the proportion of patients with unmet need, rather than patient experience itself [15]. Furness and colleagues recently reported on AYA data from the UK National Cancer Patient's Experience Survey [14]. This is an ideal survey to measure trends in quality care over time and to compare AYA responses with other age groups, as highly specific questions are asked. However, as the same questionnaire is used for all patients aged 16 and over, there are few developmentally relevant questions for AYAs. The question most comparable to our data related to trust in doctors, of whom only 72% of 16–24 year olds in the UK responded positively [14]. Another question related to the quality of communication, which 75% of the UK sample answered positively [14]. Our

Australian data compare favourably to these responses, and to a recent quantitative survey of 301 AYAs with cancer (mean age 22 at survey completion) from 25 European countries, in which 71% reported that healthcare staff treated them appropriately for their age [24].

Australian AYAs were far less positive about the quality of their physical and social environments. Whether in relation to the opportunity to be nursed in wards designed for AYAs, spend time with other young people with cancer, or talk to young people their own age, over 70% of the cohort expressed unmet need for each of these items and less than a third reported their needs had been met on the majority of items. While the quality of treatment environments has been consistently reported as a priority for AYAs with cancer across multiple countries, contexts and cultures, studies have mostly used qualitative methods [25, 26] or have asked respondents to rank or rate needs or sources of information [27, 28], rather than reporting on the proportion with unmet needs as we report here. In their systematic review of care experiences of AYAs with cancer, Bibby and colleagues reported that only 8 of 30 studies reported on age-appropriate treatment settings [15].

Australian Youth Cancer Services have focused far less than the UK on using the physical environment to shape supportive social environments for AYAs [5, 7]. The combination of Australia's small population relative to its land mass is one obvious explanation; in the UK, a critical mass of AYAs with cancer can be managed much closer to home than in Australia. While there is not robust evidence that age-appropriate cancer facilities improve patient outcomes, the consistency of patient preferences makes a strong case for co-locating AYAs in both inpatient and ambulatory settings, especially given the related benefits that come with co-locating a critical mass of health professionals [6, 29, 30]. In the absence of stand-alone AYA oncology units in Australia, several services have made efforts to partition 'pods' of designated AYA beds within wards. The potency with which this translates into consistent co-location of AYAs and improved patient experience is less clear, given the competition for bed occupancy by younger and older patients. In contrast to models of care that set out to create a critical mass of patients with the same condition (e.g. AYAs with cancer), an alternative approach is to co-locate AYAs with different health conditions within a generic AYA ward or unit [30]. Such models have been less favoured by cancer services, but positive quality of care indicators have been clearly demonstrated in the UK using this generic approach [31]. Since this study, philanthropic funding has supported the development of a small number of state-of-the-art co-designed spaces in Australian Youth Cancer Services. While future evaluation will identify the extent to which these facilities shape social interactions between AYAs and staff, the current data affirm the decision to locate these units within adult hospitals given that in addition to female sex, older AYAs and those treated in the adult sector reported higher unmet needs for AYA-specific facilities.

A key feature of cancer and its treatment in AYAs is the potential it has to disrupt social connections, interfere with intimate relationships, challenge developmental transitions between education and employment and threaten mental health [2, 9, 10, 12]. In this regard, the ability to identify major psychosocial needs is accepted as a critical component of quality AYA cancer services [2, 4, 7, 8]. Disappointingly, the frequency of psychosocial assessment appeared highly variable in this national survey; over a third reported that alcohol and drug use, safe sex and sexuality, or fear and abuse in relationships had not been discussed in the past year, notwithstanding that these are potentially life threatening issues for all young people, not just survivors of cancer [32, 33]. While it was encouraging that a high proportion of AYAs reported they have been asked about many items of relevance to a psychosocial assessment, the response pattern suggests that AYAs were less likely to be questioned about more sensitive topics. A limitation of this study is that it is not known to what extent a positive response on the psychosocial assessment questions reflects the quality of that assessment. In addition to thoroughness, confidentiality is considered a key element of quality psychosocial assessment of adolescents. It is particularly concerning that 41% of AYAs reported that they had not had the opportunity to talk privately with health care providers, regardless of age group or treatment setting. Greater use of digital technologies could overcome some of the challenges around routine psychosocial assessment, especially around sensitive topic that require confidentiality. However, these data reinforce the importance of clinical guidelines that endorse confidential health care as AYAs who had private discussions with health care providers were significantly more likely to have discussed sensitive health issues (e.g. drug use). These data also suggest that private discussions could be considered a proxy indicator of quality psychosocial assessment.

The landscape of Australian AYA cancer services is dynamic. Notwithstanding a 10-year history of AYA cancer reform, the national Youth Cancer Service network was only launched in 2011 and clinical models are still in a developmental phase [5]. The findings from this survey indicate that while many generic aspects of clinical services for Australian AYAs may at first glance be considered 'adolescent friendly' due to very high reports of staff friendliness, respect and trust, deficiencies are apparent around access to confidential psychosocial assessment and greater effort is required to promote more developmentally appropriate physical and social environments for AYAs.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

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