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General Practitioners' Management of Cancers in Australian Adolescents and Young Adults

Abstract

General practitioners (GPs) are often the first point of contact adolescents and young adults (AYAs, aged 10-29) with cancer have with the health system, and they are well-placed to coordinate their complex medical and psychosocial care. This study is the first to report characteristics of patients, GPs and cancers involved in AYA cancer management consultations in Australia, using data from a nationally-representative sample of 972,100 patient-GP encounters in 2006-2016. AYA cancers were managed in 212 encounters, equating to approximately 137 per 100,000 AYA consultations. This rate was higher in older AYAs (25-29 years) and those who held a concession card. Approximately 30% of cancers managed were classified as “new”, with GPs primarily providing counselling, education, and referrals to specialist care, imaging and pathology. This suggests that GPs are involved in the ongoing care of AYAs with cancer from diagnosis, in conjunction with other healthcare professionals. This is an encouraging indication of the potential for integrated multidisciplinary care extending from active treatment into survivorship; however, further work is needed to explore the changing role of GPs across the cancer trajectory.

Keywords: Adolescence and young adulthood; general practitioners; primary-care physicians.

Introduction

Cancer in adolescents and young adults (AYAs, here defined as 10-29 years old) accounts for 1.8% of Australian cancer diagnoses, with approximately 2300 AYAs diagnosed per year (Australian Institute of Health and Welfare, 2016); it is associated with significant physical and psychosocial burden (Kim, White, & Patterson, 2016), and is the leading cause of non-accidental death in this age group (Australian Institute of Health & Welfare, 2011). Definitions of adolescence and young adulthood vary between sources: the Australian Youth Cancer Services defines AYAs as those 15-25 years old, while the World Health Organisation includes individuals as young as 10 years and the Australian Institute of Health and Welfare (AIHW) includes individuals up to 29 years. Here, AYAs will be defined as young people aged 10-29 years, as this encompasses the broader range of ages classified as AYAs.

Cancer at this age presents unique challenges including prolonged pathways to diagnosis (Fern et al., 2013; Ng, Forsyth, Trahair, Carrington, & Anazodo, 2017), distinct tumour biology and response to therapy (Bleyer, 2009), and impacted transition to independent adulthood (Kim et al., 2016). The combined effects of the disease and its treatment frequently interfere with educational, vocational, social and developmental activities, resulting in physical and psychosocial impacts that may extend well into adulthood (Kim et al., 2016; Patterson, McDonald, Zebrack, & Medlow, 2015). Meeting the diverse needs of AYAs with cancer therefore requires coordination between different healthcare professionals in order to provide comprehensive and holistic care.

In Australia, general practitioners (GPs) are commonly the first point of contact between AYAs with cancer and the healthcare system. They are often familiar with their patients' clinical and family history, making them well-placed to coordinate AYAs' ongoing cancer care (Ng et al., 2017). GPs are essential to the holistic medical and psychosocial care of AYAs with cancer in arranging referrals, coordinating treatments and consultations, and providing ongoing disease management. However, little is known about interactions between AYAs with cancer and their GPs, and no previous studies have been conducted in Australia. This study therefore aimed to describe the management by GPs of cancer among Australian AYAs, and to report the characteristics of the patients, GPs and cancers involved.

Methods

Dataset

Data from the Bettering the Evaluation and Care of Health (BEACH) program was used to describe GP management of AYA cancers in Australian practice. BEACH was a continuous, paper-based, national study of Australian GP activity conducted between April 1998 and March 2016. The sample frame for this study was between April 2006 and March 2016. A detailed description of the BEACH methods has previously been published (Britt & Miller, 2015); in brief, during each year of data collection a national, rolling random sample of 1000 GPs each reported on 100 consecutive encounters with consenting, unidentified patients, producing a nationally representative sample of 100,000 patient-GP encounters each year. The information reported by GPs included patient demographics, patients' reasons for the encounter, and details of up to four problems managed during the consultation. Each problem was classified as either new (first presentation to a medical practitioner) or old (follow-up of previously managed problem); management data included medications, clinical treatments, procedures undertaken, pathology and imaging orders, and referrals. The BEACH program has ethics approval from the University of Sydney Human Research Ethics Committee and the AIHW Ethics Committee for the years they were a collaborator (1998-2011).

Data Management and Classification

GP consultations with AYA patients (aged 10-29 years) were the focus of this study. Cancers managed at AYA encounters were grouped by AIHW groupings (Australian Institute of Health and Welfare, 2011) as defined in Appendix A. The Australian Statistical Geographical Standard (Pink, 2011a) was used to assess the remoteness of GP practices. The Socio-Economic Indexes for Areas (Pink, 2011b) was used to classify patients as relatively socioeconomically advantaged (scores 1-5) or disadvantaged (scores 6-10), based on their residential postcodes. Consultation data were classified according to the International Classification of Primary Care, 2nd edition (ICPC-2) (Classification Committee of the World Organization of Family Doctors, 1998) and coded to the more specific ICPC-2 PLUS terminology (Britt, 1997).

Analysis

The BEACH study had a single-stage cluster design, with a cluster of consultations around each GP. In all analyses, adjustment for the cluster effects was made using survey means procedures in SAS V9.4 statistical software (SAS Institute Inc, Cary, NC,

USA). Significant statistical differences were determined by non-overlapping 95% CIs, a more conservative estimate of significance than the traditional 0.05 alpha (Julious, 2004).

Results

In total, 9,721 GPs participated in the BEACH project recording details for 972,100 patient encounters. There were 154,847 encounters with patients aged 10-29 years, 212 of which involved cancer management. The rate of AYA cancer management was 136.9 per 100,000 AYA patient encounters, with carcinomas (63.3 per 100,000 encounters), melanomas (23.2) and lymphomas (14.2) the most commonly managed (Table 1).

[Table 1]

Patient Characteristics

Table 2 shows the rates of cancer management consultations for different socio-demographic patient groups. AYAs aged 25-29 years had a significantly higher cancer management rate than younger AYA patients (10-24 years). AYA patients who held a Commonwealth Concession Card¹ had a significantly higher cancer management rate than those who did not. There was no significant difference in the cancer management rate by patient sex, language background, relative socioeconomic advantage/disadvantage, or whether the patient was new to the practice (Table 2).

[Table 2]

GP Characteristics

Table 2 shows the rates of cancer management consultations for different GP groups. There was no significant difference found in the cancer management rate by GP sex, GP age, whether the GP was an Australian graduate, or by practice location.

AYA Cancer Characteristics

Of the 212 cancer cases managed, 29.2% were considered “new” cases by GPs. GPs most commonly used non-pharmacological treatments (30.7% of AYA cancers managed at GP encounters) in their management of AYA cancers, predominantly counselling, advice or education about the cancer and its treatment, and excisions for biopsy. GPs also frequently referred patients to other health professionals (29.7%), such as gynaecologists, dermatologists and oncologists. Medications were only recorded at 16.0% of consultations. Pathology

¹ A government-provided entitlement card which entitles the holder to subsidised medications under the Pharmaceutical Benefits Scheme, in addition to some other state and local government concessions.

(17.9%) and imaging (10.4%) procedures were also regularly ordered in the management of AYA cancer (Table 3).

[Table 3]

Discussion

Unsurprisingly the management of AYA cancers by Australian GPs is relatively uncommon, making up just 0.02% of the consultations in this study and 0.14% of consultations involving the 10-29 year old age group. Carcinomas were the most common cancer type managed by GPs, reflecting the incidence of multiple cancer subtypes including some with earlier onsets (such as thyroid, breast and colorectal cancers). Likewise, melanomas and lymphomas are amongst the most common cancers diagnosed in Australian AYAs (Roder, Warr, Patterson, & Allison, 2018), and this was reflected in the distribution of AYA cancers managed during patient-GP encounters. Additionally, cancer management consultation rates varied between socio-demographic groups, with results suggesting that older AYAs and those holding a Concession Card consult their GPs about cancer at higher rates compared with younger patients and those who do not hold a Concession Card.

The significantly higher cancer management rate among older AYAs (aged 25-29 years) relative to younger groups may reflect the increasing risk of being diagnosed with cancer with age (Australian Institute of Health and Welfare, 2017), which is thought to be linked to acquired genetic mutations associated with cumulative exposures to carcinogens across the lifespan (Bleyer, Viny, & Barr, 2006). The observed difference in consultation rates suggests a potential distinction between 25-29 year olds and younger AYA patients. Together with evidence that different cancers begin to peak and wane in the 20s (Bleyer et al., 2008; Bleyer, O'Leary, Barr, & Ries, 2006; Howlader et al., 2015), this suggests that older AYAs are better considered as a separate cohort. This also validates the Australian Youth Cancer Services' focus on working with 15-25 year olds in the provision of age-appropriate medical and supportive care.

Reasons for the higher cancer consultation rate among AYAs holding a Commonwealth Concession Card are less clear, given that eligibility for Concession Cards may reflect multiple factors (e.g. unemployment, sickness or carer status). As benefits associated with these cards include reduced out-of-pocket medical expenses (bulk billing)

and subsidised prescription medications, AYAs with Concession Cards may also be more financially able to consult medical practitioners about health issues like cancer. Alternatively, AYAs who do not have Concession Cards may instead be covered by private health insurance, and may be utilising this to seek specialist care rather than consulting GPs about the management of their cancers. However, there were no significant differences in the cancer management rate by patient sex, language background, relative socioeconomic advantage/disadvantage, or whether the patient was new to the practice.

Notably, a higher proportion of these AYAs were classified as new to the practice (11.8%) relative to the overall BEACH sample (7.9%; 95% CI 7.7-8.1), perhaps because younger patients are less likely to consult GPs and to have a regular practice that they are linked to (Britt & Miller, 2009). This suggests that a considerable number of AYAs may have limited experience or familiarity with GPs managing their cancers – indeed, it is not uncommon for American AYAs (18-39 years) diagnosed with cancer to report not having a primary care physician (Kinahan et al., 2017). Additionally, 29.2% of the AYA cancers managed in this study were reportedly “new” cases, suggesting that a substantial part of GPs’ management of AYA cancers relates to the initial diagnosis.

Perhaps accordingly, GPs’ reported management strategies appeared to be more advisory, primarily providing counselling and education to patients and referring them to pathology, imaging or further specialist care. The high proportion of “old” cancers managed suggests that GPs are also involved in the ongoing care of AYA patients – an encouraging finding, as this lays the foundations for longer term follow-up care as AYAs move into the survivorship phase (Kinahan et al., 2017). However, it is not clear whether these AYAs are returning to the same GP for ongoing care; it is possible that some are moving between medical practitioners, although the low proportion of AYAs who are new to practice suggests that this is relatively uncommon. Here, a comparison of management strategies for “new” and “old” cancers may be able to further elucidate the role of GPs through the cancer trajectory, from diagnosis to survivorship; however, this study had insufficient statistical power to undertake these analyses.

Although the BEACH dataset comprised almost one million records of GP encounters over ten years, only 212 reported consultations involved the management of AYA cancers. While reflecting the rarity of AYA cancers, the small sample of AYA cancer encounters and the subsequent limited statistical power may have been insufficient to detect other smaller

effects. In particular, potential differences (not statistically significant) in cancer management rates were observed for patient language background, GP graduation country, and practice remoteness. It is possible that a larger sample would be sufficiently powered to detect differences in these domains. The BEACH dataset also provides limited information about the broader interactions between GPs and AYAs diagnosed with cancer. For example, while reports of referrals and whether the cancer is a “new problem” are interesting, these cross-sectional encounter records do not indicate whether GP management of AYA cancers is ongoing or handed over to more specialised clinicians. Finally, although the BEACH dataset is representative of the Australian population, these findings may not generalise to other countries- particularly where cancer care coordination does not consider ongoing GP-patient relationships or government subsidies for healthcare costs are more limited.

This study provides a first glimpse into GPs’ role in the care of AYAs with cancer in Australia, and is the first descriptive study of these encounters. Despite the low number of AYA cancer management consultations in the dataset, findings are notable in highlighting GPs’ management of both new and old cases of AYA cancers, suggesting that GPs play a continuing role in supporting AYAs through education, counselling and coordination of referrals throughout diagnosis and treatment. However, further work is needed to extend this research by exploring patient-GP interactions across the cancer trajectory, providing a more complete picture of the GPs’ role in the ongoing management of AYA cancers.

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Appendix 1

Classification of Adolescent and Young Adult Cancers

Cancer Grouping	AIHW Classification
Bone cancers	Ewing tumour Osteosarcoma Other bone tumour
Carcinomas	Breast (females only) Cervix Colorectal (including anus) Thyroid Other carcinomas (including breast in males and skin)
Central Nervous System cancers	Glioblastoma and anaplastic astrocytoma Other astrocytoma, glioma or ependymoma Medulloblastoma Supratentorial primitive neuroectodermal tumour Other CNS tumour
Germ cell cancers	Gonadal Non-gonadal
Leukaemias	Acute lymphoid leukaemia Acute myeloid leukaemia Other leukaemia
Lymphomas	Hodgkin lymphoma Non-Hodgkin lymphoma
Melanomas	Melanomas
Soft-tissue sarcomas	Rhabdomyosarcoma Other soft-tissue sarcoma
Other and unspecified	-

Table 1

Rate of Specific Cancer Management per 100,000 AYA Encounters, 2006-2016

Cancer	Rate per 100,000 AYA GP encounters (95% CIs)
Carcinomas	63.3 (50.0-76.6)
Melanomas	23.2 (15.3-31.2)
Lymphomas	14.2 (8.3-20.1)
Leukaemias	8.4 (3.8-13.0)
Other & Unspecified Cancers	6.5 (2.5-10.5)
Central Nervous System Cancers	5.2 (1.2-9.2)
Soft Tissue	5.2 (1.6-8.7)
Bone Cancers	5.2 (1.6-8.7)
Germ Cell	5.2 (1.6-8.7)
All Cancers	136.9 (117.5-156.3)

Table 2

Rates of Specific Cancer Management per 100,000 AYA Encounters by Patient and GP

Characteristics, 2006-2016

Characteristic	Number of AYA encounters	Number of AYA cancer encounters	Rate per 100,000 AYA encounters (95% CIs)
Patient sex (Missing)	(947)	(1)	
Male	54,865	71	129.4 (98.2-160.6)
Female	99,035	140	141.4 (117.2-165.6)
Patient age (Missing)	(0)	(0)	
10-14 years	23,082	20	86.6 (48.7-124.6)
15-19 years	34,988	32	91.5 (55.2-127.7)
20-24 years	46,213	58	125.5 (93.4-157.6)
25-29 years	50,564	102	201.7 (162.0-241.4)
Commonwealth Concession card (Missing)	(15,211)	(16)	
Commonwealth Concession card	37,704	72	191.0 (147.1-234.8)
No Commonwealth Concession card	101,932	124	121.6 (98.9-144.4)
Language background (Missing)	(18,325)	(19)	
English speaking	124,876	173	138.5 (116.9-160.2)
Non English speaking	11,646	20	171.7 (97.1-246.4)
Relative advantage/disadvantage (Missing)	(3,464)	(5)	
Advantaged	95,486	125	130.9 (106.4-155.5)
Disadvantage	55,897	82	146.7 (114.5-178.9)
New to practice (Missing)	(1,855)	(1)	
New to practice	22,440	25	111.4 (66.2-156.6)
Seen previously	130,552	186	142.5 (121.1-163.8)
GP sex (Missing)	(0)	(0)	
Male	87,685	117	133.4 (107.9-159.0)
Female	67,162	95	141.4 (111.7-171.2)
GP age (Missing)	(1,135)	(1)	
<45 years	50,476	63	130.2 (96.4-164.0)
45-54 years	54,847	73	144.6 (108.9-180.3)
55+ years	48,389	75	136.7 (104.9-168.6)
Australian GP graduate (Missing)	(459)	(0)	
Australia graduate	102,222	127	124.2 (101.9-146.6)

Overseas graduate	52,166	85	162.9 (125.6-200.2)
GP practice geography (Missing)	(249)	(0)	
Major city	114,162	147	128.8 (106.8-150.7)
Inner regional	26,098	34	130.3 (83.2-177.4)
Outer regional/remote	14,338	31	216.2 (138.9-293.5)

Note: Missing data removed for analyses

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Table 3

Management of AYA Cancers by General Practitioners, 2006-2016

	Proportion of AYA cancers managed at GP encounters^c (95% CIs)
“New” cases	29.2% (22.6-35.8)
At least one medication	16.0% (11.0-21.1)
Opioid	5.7% (2.3-9.0)
At least one nonpharmacological treatment	30.7% (24.2-37.1)
Counselling/advice/education	16.5% (11.3-21.7)
Excision/biopsy/destruction/cauterisation	4.7% (1.9-7.6%)
At least one referral	29.7% (23.4-36.1)
Gynaecologist	6.6% (3.2-10.0)
Dermatologist	5.2% (1.9-8.5)
Oncologist	4.7% (1.8-7.6)
At least one pathology test ordered	17.9% (12.7-23.1)
At least one imaging test ordered	10.4% (6.0-14.7)

^cManagement statistics are specific to the AYA cancers managed, and exclude management strategies for other issues discussed in the same encounter