Use of support services in a sample of patients with high-risk primary melanomas in urban, regional and rural Queensland

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ustralia has one of the highest melanoma incidence rates worldwide.¹ The prognosis of localised melanoma is largely dependent on tumour thickness, where thin (<1 mm) melanomas are potentially curable with surgical excision and have 20-year survival rates as high as 96% in Queensland.^{2.3}. In contrast, localised thick (>4 mm) melanomas are associated with a 39% 10-year survival rate.²

The diagnosis of cancer can cause significant psychological distress and reduce quality of life of cancer patients and their family members.⁴ Psychological distress appears to be higher in patients whose disease is at high risk of progression and is associated with poorer prognosis.⁵⁻⁷ We recently demonstrated that a substantial proportion of newly diagnosed patients with locally invasive primary melanoma have unmet needs, particularly for information on melanoma recurrence, prognosis and psychosocial supports.⁵ Patients with primary melanoma also experienced significantly lower emotional wellbeing than general population norms.⁵ Accessing health information, counselling services or community support services may enhance patients' understanding of their disease and improve psychosocial wellbeing.⁸⁻¹⁰ In addition to psychological support, melanoma patients may require physical therapies to cope with cancer fatigue and/or physical symptoms experienced

Abstract

Objective: To characterise use of support services in patients diagnosed with high-risk primary melanoma by their location of residence.

Methods: In a cross-sectional study of 787 patients with histologically-confirmed clinical stage 1B-2 melanoma, we estimated odds ratios (ORs) using regression models to assess the association of support service use with residence in rural, regional or urban areas. We also evaluated demographic and clinical correlates of support service use.

Results: Among 113 rural patients, 33 (29%) used support services around time of diagnosis compared to 88 (39%) of 224 regional participants and 164 of 448 (37%) urban participants. Regional participants more commonly used support services compared to rural participants (OR 1.84; Cl 1.09-3.10), but there was no association with urban versus rural residence (OR 1.32; Cl 0.82-2.13). As well, females (OR 1.58; Cl 1.15-2.18), those <65 years (OR 1.96; Cl 1.42-2.71), or with higher education (OR 2.30; Cl 1.53-3.44), or those with T-stage 4B (OR 2.69; Cl 1.36-5.32) were more likely to use support services than other patients.

Conclusion: Use of support services is lower among rural patients and other sub-groups of primary melanoma patients who have poorer prognoses than others.

Implications for public health: Appropriate triage to support services is required for rural and other vulnerable patient groups to ensure optimal patient care.

Key words: melanoma , support services , remoteness of residence , Queensland, high-risk patients

after lymph node biopsies or dissections.^{11,12} A multidisciplinary approach to patient's psychosocial and physical needs is seen as essential to cancer care.¹³

Many general and melanoma-specific support services are available to Queensland patients, ranging from standard primary care, allied health and mental health services to internet- or phone-based or group counselling services.¹⁴ Patients in regional and remote areas within Australia may have limited access to some of these services due to barriers such as the need to travel large distances, financial costs and limited internet access.¹⁵ Furthermore patients in regional and remote areas in Australia have poorer melanoma survival rates and thus they may be particularly vulnerable to having elevated supportive care needs associated with their poorer prognosis.^{16,17} It is unknown however

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whether support service use differs among melanoma patients according to their geographic location.

We aimed to determine whether use of support services differs for Queensland patients with primary melanomas at high risk of progression, depending on location of residence (urban, regional or rural). We also identified and adjusted for other correlates of support use in this cohort.

Methods

Study population

Participants were recruited prospectively between October 2010 and October 2014 from a variety of specialist public hospital clinics, private practices of surgeons associated with the participating public hospitals, and through the three main private pathology services in Queensland. The public hospitals recruiting eligible patients included Princess Alexandra Hospital, Royal Brisbane and Women's Hospital, Nambour General Hospital and Townsville General Hospital.

Participants were required to have a histologically-confirmed new diagnosis of stage 1B or 2 cutaneous melanoma, be aged 17 years or older, and have the capacity to complete the study questionnaire. Eligible patients identified through clinics were invited to participate by their treating doctors (or by study personnel with doctor's permission) and received study information, consent form and a questionnaire. Laboratory pathologists identified patients and included a standard note on eligible patients' histopathology reports, which informed treating doctors about the study and asked doctors to inform the pathological company if their patients should not be contacted. Patients for whom no objection was raised within two weeks were sent information about the study with request for permission to release their details to study personnel. Those who agreed were contacted and written consent was obtained from all participants. The study was approved by the Human Research Ethics Committees of the Metro South Hospital, the Health Service of the Princess Alexandra Hospital (HREC/11/ QPAH/470 [Metro South]: 12/10/2010) and the OIMR Berghofer Medical Research Institute (P1305 [QIMR]: 2/9/2010).

Data collection

Personal details including previous melanoma history (yes/ no), skin examination

history (never/every few years/at least yearly) and use of sunglasses, hat, sunscreen and protective clothing (each classified as never/ sometimes/mostly), were collected for each participant at recruitment with a standard self-completed questionnaire. Histology reports were obtained for all self-reported previous melanomas. Socioeconomic factors ascertained via the questionnaire included employment status (employed/unemployed/ retired), relationship status (partner/no partner) and highest level of education (less than year 12/technical college or diploma/ University). Details of all primary melanomas were extracted from histopathology reports including thickness (mm) and presence of ulceration (yes/no) or mitosis (per mm²). Pathology reports also provided information on the specialty of the doctor who performed the diagnostic biopsy, the time from biopsy to surgical treatment and public versus private health sector use. Clinical and tumour (T) stages were classified in accordance with the 2009 American Joint Committee on Cancer (AJCC) Melanoma Staging system.²

Patients' use of support services in relation to their melanoma diagnosis, treatment or recovery was indicated on a tick-box list on the self-completed questionnaire (Supplementary Figure 1, available online). In order to reflect modalities of support service delivery, services were grouped into either: 1) Health providers: where support or counselling was provided by a doctor or psychiatrist, psychologist, social worker, mental health care team, physiotherapist, community health nurse, exercise physiologist, dietician, pain specialist or respite care; 2) Information services: written (information sheet), phone (cancer helpline, tele-based cancer counselling) or internetbased (internet information, internet-based support group); or 3) Community support services: peer support or community groups (including community-based support groups, relaxation/meditation class and education program/workshop).

Data analysis

Each patient's place of residence was categorised using the Australian Statistical Geographical Classification- Remoteness Area (2001) (ASGC-RA). Postcodes were classified as *major city (urban), inner regional* and *rural* (the combination of outer regional, remote or very remote). Sun protection behaviours were combined into a summary score. Chi-square, t-test and ANOVA tests were used to determine if demographic, behavioural or clinical factors of interest or use of support services were significantly different by location of residence, classified as urban, inner regional and rural. Logistic regression models were used to estimate odds ratios as a measure of the association between support service use and location of residence while adjusting for known prognostic factors (age, sex and tumour stage) and other confounding factors (education and employment) (Supplementary Table 1, available online). Logistic regression models were also used to evaluate associations with demographic (age, sex, education) and clinical (tumour stage at diagnosis) factors and support service use. All statistical analyses were performed using SAS software version 9.4.

Results

Of the 1,254 invited patients, 825 (66%) consented to take part. A further 38 were found to be ineligible after consent, leaving 787 study participants. The mean age at diagnosis was 62 years, 57% of participants were male, and 21% had a histologically confirmed past history of melanoma (Table 1). The study cohort showed no significant differences in age or sex distributions when compared with total number of cases aged less than 80 years diagnosed in Queensland within the study period as recorded by the Cancer Registry.¹⁸

Rural and inner regional participants were less likely to have university degrees (p=0.03), and inner regional participants were more commonly retirees (p=0.03) (Table 1). Rural participants were less likely to report receiving at least yearly skin examinations and they more commonly reported no past history of a skin check compared to urban and inner regional participants (p=0.006) (Table 1). The specialty of the medical practitioner who diagnosed the primary melanoma, differed by remoteness of residence. General Practitioners (GPs) more commonly diagnosed melanomas in rural and inner regional areas compared to urban areas (70% rural; 68% inner regional; 55% urban). GPs working in specialised skin cancer clinics more commonly diagnosed melanomas in urban areas (23% urban versus 13% in rural areas) and dermatologists diagnosed 13% of melanomas in urban areas, but only 4% in rural areas (p<0.001) (Table 1). Time from

biopsy to follow-up surgery increased with distance from urban areas (urban: 24 days, inner regional: 28 days and rural: 33 days) (Table 1).

A total of 37% of participants reported use of support services in relation to their melanoma around the time of diagnosis. Overall, the proportion who used at least one support service was lower in rural areas (29%) than in regional (39%) or urban areas (37%) (p=0.09) (Table 2). Across the state, participants most commonly sought information-based support, with 22% of participants sourcing information from the internet, 7% obtaining written information and 1% receiving information via the phone. Health providers and community support services were used by 17% and 13% of participants respectively. With the exception of peer support, where rurality was associated with less peer support use (p=0.01), no differences in specific types of support use were detected by geographic location (Table 2).

After adjustment for prognostic and confounding variables patients residing in regional areas compared to those in rural areas were significantly more likely to use support services (OR 1.84, 95% CI 1.09-3.10) but there was no association with urban residence (Table 3). Sex, age, level of education, and melanoma T-stage were also associated with use of at least one support service. Females were more likely to use support services than males (OR 1.58, 95% CI 1.15-2.18) and participants under the age of 65 were twice as likely as older participants to use support services (OR 1.96, 95% CI 1.42-2.71) (Table 3). Those with a university degree (OR 2.30, 95% CI 1.53-3.44) or a diploma or trade (OR 1.43, 95% CI 1.00-2.06) were more likely to have used a support service compared with participants who reported grade 12 high school or less as their highest level of education. Participants with most advanced T-stage (4B) were more likely to use support services than earliest stage (1B/2A) patients (OR 2.69, 95% CI 1.36-5.32).

Discussion

We found differences in socioeconomic status and clinical features of melanoma patients in urban, regional and rural areas within Queensland. A greater proportion of rural and regional patients were socioeconomically disadvantaged and had less frequent skin checks. Use of support services differed by location of residence, whereby participants Table 1: Demographic, behavioural and clinical characteristics of cohort by location of residence using the ASCG-RA

classification.					
	Overall	Urban (major city)	Inner regional	Rural (Outer	
	(n=787)	(n=450, 57%)	(n=224, 29%)	regional/ remote/	
				very remote)	<i>p</i> -value
				(n=113, 14%)	
	n (%)	n (%)	n (%)	n (%)	
Sex			407 (57)	((4))	
Male	447 (57)	252 (56)	127 (57)	68 (60)	0.7ª
Female	340 (43)	198 (44)	97 (43)	45 (40)	
Age (years)				/>	
Mean (SD)	62 (14)	61 (14)	64 (13)	60 (14)	0.052
Relationship status					
No partner	199 (25)	117 (26)	54 (24)	28 (25)	0.9ª
Partner	586 (75)	333 (74)	169 (76)	84 (75)	
Education					
High school or less	403 (51)	221 (49)	123 (55)	59 (52)	0.035ª
Trade/ diploma	228 (29)	122 (27)	69 (31)	37 (33)	
University	155 (20)	106 (24)	32 (14)	17 (15)	
Paid Employment					
Yes	339 (45)	212 (48)	73 (34)	54 (50)	0.003 ^a
No	53 (7)	34 (8)	12 (6)	7 (7)	
Retired	366 (48)	193 (44)	127 (60)	46 (43)	
Sun protection behaviours					
Never	125 (16)	70 (16)	39 (17)	16 (14)	0.6ª
Sometimes	427 (54)	250 (56)	121 (54)	56 (50)	
Mostly	235 (29)	130 (29)	64 (29)	41 (36)	
Skin check by doctor					
Never	153 (20)	75 (17)	44 (20)	34 (31)	0.006 ^a
Every few years	236 (31)	144 (33)	59 (27)	33 (31)	
At least yearly	380 (49)	222 (50)	117 (53)	41 (38)	
Past history of melanoma	164 (21)	102 (23)	42 (19)	20 (18)	0.3ª
Qualification of biopsy Doctor					
GP	474 (61)	245 (55)	150 (68)	79 (70)	<0.001ª
GP- skin clinic	159 (20)	101 (23)	43 (19)	15 (13)	
General Surgeon	27 (3)	10 (2)	11 (5)	6 (5)	
Plastic Surgeon	41 (5)	33 (7)	4 (2)	4 (4)	
Dermatologist	79 (10)	60 (13)	14 (6)	5 (4)	
Time from biopsy to surgery (days)					
Mean (SD)	27 (21)	24 (16)	28 (20)	33 (35)	0.0006 ^b
Time from biopsy to questionnaire (days)					
Mean (SD)	40 (25)	37 (23)	44 (27)	43 (23)	0.002 ^b
Health sector					
Public	351 (45)	201 (45)	107 (48)	43 (38)	0.2ª
Private	436 (55)	249 (55)	117 (52)	70 (61)	
Thickness					
<1 mm	206 (26)	127 (28)	49 (22)	30 (27)	0.2ª
1-2 mm	334 (43)	196 (44)	89 (40)	49 (43)	
2-4 mm	176 (22)	89 (20)	62 (27)	25 (22)	
>4 mm	69 (9)	36 (8)	24 (11)	9 (8)	
T-stage					
1B/2A	465 (60)	281 (63)	120 (54)	64 (57)	0.006ª
2B/3A	193 (25)	108 (24)	52 (23)	33 (29)	
3B/4A	87 (11)	35 (8)	38 (17)	14 (12)	
4B	40 (5)	24 (5)	14 (6)	2 (2)	
SLNB					
Negative	222 (85)	110 (82)	63 (89)	49 (89)	0.3ª
Positive	38 (15)	24 (18)	71 (11)	6 (11)	
a: Results of chi-squared test	/	. /	. /	. /	
b: Results of ANOVA test					

residing in regional areas more commonly utilised support services compared with those residing in rural areas. No statistically significant difference was observed between urban and rural participants, which is likely due to small numbers in the rural cohort. We also found higher use of support services in female participants, those with higher education or younger age (<65 years) or those diagnosed with advanced primary melanomas (T-stage 4B).

Non-Indigenous Australians residing rurally have poorer melanoma survival than those residing in urban areas, yet survival does not differ between regional and urban patients.¹⁶ Indeed, patients diagnosed with advanced/ metastatic melanoma often re-locate from rural areas to larger communities to improve access to medical services.¹⁹ Migration from rural to regional areas also occurs in the elderly and/or retired populations,²⁰ and this was reflected in our study participants. Socioeconomic status including education level and employment, was lower among regional and rural study participants. This is consistent with the lower rate of high school completion observed generally in the rural population.^{21,22} Lower levels of educational attainment have been linked to greater risks in late-stage melanoma diagnosis.23 Within the restrictions of our cohort however (primary invasive melanoma) we did not observe a difference in melanoma thickness in rural participants.

Table 2: Use of health, information and community services by location of residence using the ASCG-RA classification.						
Support service use	Urban	Inner regional	Rural	<i>p</i> -value		
	n (%)	n (%)	n (%)			
Any	164 (37)	88 (39)	33 (29)	0.09		
Health provider						
Counselling provided by doctor	55 (12)	29 (13)	10 (9)	0.5		
Allied health provider	23 (5)	13 (6)	5 (4)	0.9		
Information						
Internet resources	99 (22)	45 (20)	22 (19)	0.7		
Phone resources	6 (1)	1 (0.5)	2 (2)	0.5		
Written information	33 (7)	18 (8)	8 (7)	0.9		
Community support						
Peers	43 (10)	11 (5)	3 (3)	0.01		
Community groups	13 (3)	4 (2)	0 (0)	0.1		

The distribution of medical practitioners and surgical specialists in Australia favours urban areas. In accordance with this distribution and the accessibility of GPs, GPs in skin cancer clinics and specialist practitioners (dermatologists and surgeons), we observed that the proportion of melanomas diagnosed by either a specialist or skin cancer-specific GP was lower in rural areas.²⁴ Frequent skin examinations performed by a medical practitioner result in increased detection of thin melanomas;^{25,26} we observed that urban patients (who received skin checks most frequently) were also more commonly diagnosed with thinner melanomas. Skin examination frequency in rural participants was significantly lower which demonstrates an important secondary prevention discrepancy in this population.

Table 3: Factors associated with use of support services.						
	Use of health service	OR adjusted ^a	OR adjusted ^b			
	n (%)	OR (95% CI)	OR (95% CI)			
Sex						
Male	142 (32)	1.00 (Ref)	1.00 (Ref)			
Female	143 (42)	1.53 (1.13-2.08)	1.58 (1.15-2.18)			
Age (years)						
>65	106 (28)	1.00 (Ref)	1.00 (Ref)			
<65	179 (44)	2.03 (1.49-2.75)	1.96 (1.42-2.71)			
Education						
High school or less	118 (29)	1.0 (Ref)	1.00 (Ref)			
Trade/ diploma	88 (39)	1.44 (1.00-2.06)	1.43 (1.00-2.06)			
University	78 (50)	2.29 (1.53-3.42)	2.30 (1.53-3.44)			
T-stage						
Stage 1B/2A	169 (37)	1.00 (Ref)	1.00 (Ref)			
Stage 2B/3A	64 (33)	0.98 (0.68-1.42)	1.04 (0.71-1.52)			
Stage 3B/4A	30 (35)	1.17 (0.71-1.93)	1.21 (0.72-2.04)			
Stage 4B	22 (55)	2.68 (1.37-5.22)	2.69 (1.36-5.32)			
Location of residence						
Rural	33 (29)	1.00(Ref)	1.00(Ref)			
Regional	88 (39)	1.83 (1.08-3.08)	1.84 (1.09-3.10)			
Urban	164 (37)	1.33 (0.83-2.15)	1.32 (0.82-2.13)			
a: Adjusted for age, sex, melanoma T-	stage					

b: Adjusted for age, sex, melanoma T-stage, employment and education

Fewer rural participants used support services after their melanoma diagnosis, treatment and during recovery, compared with urban and regional participants. In particular rural participants were less likely to use community support. This may reflect cultural attitudes towards group supports, the barrier of distance and/or lack of availability of such services. The only support service favoured by rural participants was telephone counselling/ information, although this subgroup analysis was not sufficiently powered to demonstrate a significant association. Our study also demonstrates that females, younger patients and those with higher education are more commonly accessing support services. Overall within our study around a third of participants utilised support services and the most commonly accessed were the internet (to obtain information about the disease) and counselling by doctors. Structured support groups and programs are effective at meeting patient's needs for information, emotional and practical support and have been shown to improve emotional wellbeing.^{8,9,27} Use of structured support groups is generally suboptimal amongst cancer patients and we also demonstrate poor uptake of support group use within our cohort (2%).²⁷ Hence facilitating uptake of support service use in these patients may promote wellbeing.27 Barriers to accessing services may consist of patient factors (lack of knowledge, socioeconomic limitations, etc) and health system factors (inequitable distribution of services and service providers).²⁸⁻³⁰ Patients from rural communities may be further disadvantaged due to lack of infrastructure development, cost pressures associated with distance and location, and longer travel times^{15,19} but despite these limitations, type of support service used did not differ

by location of residence. Further research is required to identify barriers to support services in rural and other vulnerable populations that can be removed or modified. We also recommend that specialist and primary care physicians be encouraged to triage their high-risk melanoma patients to support services in order to prevent undue distress and optimise their mental and physical wellbeing. Early engagement with support services would also allow early detection of patients requiring more intensive psychological or physical therapies.

The strengths of these results are their being based on a large cohort of primary melanomas at high risk of spread, with detailed clinical and histological data obtained from pathological reports. The results do not pertain to melanoma patients presenting with nodal or distant metastasis. This study had several design limitations. Firstly, use of support services was measured via a self-reported mail survey and therefore was subject to recall bias and variation in interpretation of the questions. It likely that participants have under-reported their use of support services but under-reporting and variation in interpretation would be uniform across rurality and other subgroups of interest. These limitations are therefore likely to have had an effect on power in our analysis but would not have changed the conclusions of our comparisons between subgroups. Secondly, although we recruited many patients via tertiary referral centres which potentially introduced sampling bias, many were recruited through primary care and indeed we demonstrated comparability of the study cohort to melanoma patients from the Queensland Cancer Registry within the study period.¹⁸ Finally, we used the ASCG-RA remoteness of residence classification system whose suitability may be suboptimal for areas categorised as 'rural', because 'rural' contains areas such as Townsville and Cairns that have melanoma referral centres. Using the ASCG-RA classification system is therefore likely to under-estimate true 'rural' differences analysing use of support services.

Conclusion

Use of support services is lower among highrisk primary melanoma patients who reside in rural areas, who are male, elderly or have low education, and yet these groups have poorer prognosis than others. On the other hand patients with T4B more commonly used support services compared to those with T1B/2A. Melanoma patients are known to suffer from poorer psychological wellbeing compared to the general population.⁵ Appropriate triage to support services is required to ensure optimal care.³¹ Further ways to deliver services to rural residents and break down the barriers in service uptake among these residents as well as other vulnerable groups should be identified in order to promote emotional and physical wellbeing and identify patients in need of specialist services.

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Supporting Information

Additional supporting information may be found in the online version of this article:

Supplementary Table 1: Demographic, behavioural and clinical characteristics of cohort by support service use.

Supplementary Figure 1: Tick-box question on self-completed questionnaire assessing patients' use of support services in relation to their melanoma diagnosis, treatment or recovery.