



Patient-reported outcomes in melanoma survivors at 1, 3 and 5 years post-diagnosis: a population-based cross-sectional study

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Abstract

Purpose There is a lack of population-based data describing patient reported outcomes (PROs) in melanoma survivors which could guide the development of interventions and resources. This study assessed overall quality of life (QoL), self-reported symptoms and unmet information needs in melanoma survivors 1, 3 or 5 years post-diagnosis.

Methods A cross-sectional postal survey was conducted in Victoria, Australia, with eligible melanoma survivors identified from a population-based cancer registry. Patient-reported outcome measures included the EuroQoL 5-Dimension 5-Level (EQ-5D-5L), and self-reported symptoms, difficulties and information needs. Associations between demographic, disease and care-related factors and QoL were also assessed.

Results A total of 476 melanoma survivors participated in the study (response rate 46.5%). Anxiety and depressive symptoms were more prevalent in survivors compared to the general population (30.7% vs 21.6%; $p < 0.01$). Fear of cancer recurrence (48.3%) and fear of cancer spreading (37.8%) were the most commonly reported symptom items, and approximately one in five melanoma survivors had unmet information needs related to psychological aspects of living with melanoma. Recurrent melanoma, living in a nursing home, chronic comorbidities, and melanoma diagnosed at > 2 mm thickness were associated with lower QoL.

Conclusion A large proportion of melanoma survivors reported ongoing quality of life deficits, fear of cancer recurrence, as well as unmet information needs up to 5 years after diagnosis. Patients may benefit from tailored informational resources and interventions that address the psychological aspects of living with and beyond melanoma.

Keywords Survivorship · Melanoma · Patient-reported outcomes · Quality of life

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Introduction

Melanoma is one of the most common cancers in Australia, accounting for 10% of all cancer diagnoses [1]. The 5-year survival rate is 90%, creating a significant population of people living beyond a melanoma diagnosis [1]; however, there is limited data regarding survivors' experiences and the impact of diagnosis and treatment on quality of life (QoL).

Available evidence indicates melanoma survivors experience substantial physical and psychological burden [2]. A German registry-based cohort study reported greater physical symptoms, depression, and a decline in physical, role, cognitive and social functioning 8 years post-diagnosis compared to the general German population [3]. Other studies show that over 70% of people with a history of melanoma report high levels of fear of cancer recurrence (FCR), and about 30% report psychological distress warranting clinical intervention [4, 5].

There is a lack of population-based data describing PROs in melanoma survivors in Australia, representing an important knowledge gap as this data may be used to inform interventions, service delivery and models of care. In 2011, the United Kingdom's National Health Service (NHS) conducted a pilot survey to collect PROs from cancer survivors up to 5 years post-diagnosis using a population-based sampling approach [6]. The Victorian Comprehensive Cancer Centre (VCCC) conducted a similar study to investigate PROs in Victorian cancer survivors [7].

The objectives of this study were to describe the QoL, self-reported symptoms and unmet information needs in a representative sample of Victorian melanoma survivors who were either 1, 3 or 5 years post-diagnosis, and to assess the demographic-, disease- and care-related factors that influence self-reported health status.

Methods

Participants

A cross-sectional study of Victorian residents aged ≥ 18 years, diagnosed with melanoma 1, 3 or 5 years earlier. Cases were excluded if had multiple invasive primaries, Clark level < 2 disease, if their treating doctor advised against participation (reasons given included limited English and serious comorbid conditions), or if previously approached by the Victorian Cancer Registry (VCR) for study participation.

Procedure

Cases were identified from the VCR database and contacted from February to August 2014. Participants were posted a study information sheet, questionnaire and reply-paid

envelope, and reminders were sent to non-responders after 3 weeks. Consent was implied by return of the questionnaire. No incentives were offered. Comparative population data were sourced from the Dual-Frame Omnibus Survey, a 2011 survey of Australian residents aged ≥ 18 years [8].

Questionnaire

Data collection followed methods of an earlier study conducted in the UK [6]. Participants completed the EuroQoL 5-Dimension 5-Level (EQ-5D-5L), containing five QoL items assessing mobility, personal care, usual activities, pain/discomfort, and anxiety/depression [9]. Australian index values were calculated from Norman et al. [10]. Self-report data on symptoms, unmet information needs, treatment response and disease status, presence of long-term conditions other than cancer, perceptions of clinical care and support, and demographic data not provided by the VCR were also collected.

Weighting and estimation

Weights were calculated for each respondent to ensure results were representative of the population of eligible cases using iterative proportion fitting implemented in R [11]. The variables used for weighting were years since diagnosis, age at diagnosis, geographic location and gender. Weights were used in making estimates of item proportions and averages, together with their standard errors and confidence intervals.

Statistical analysis

Statistically significant differences between groups were determined through application of *t* tests to the weighted estimates, with *p*-values adjusted for multiple comparisons. Results were considered significant if the adjusted *p*-values were 0.05 or less. Linear regression analysis was used to explore relationships between QoL and demographic, disease and treatment-related variables. Continuous variables, such as the QoL measures, were standardised (transformed to have a mean of zero and a standard deviation of one) to assist in the interpretation of results.

Results

The overall response rate was 46.5% (476/1024); 52.6% (205/390) at 1 year, 44.3% (133/300) at 3 years and 41.3% (138/334) at 5 years post-diagnosis. Almost one-third (29.0%) of participants were aged 60–69 years, and most had superficial spreading melanoma (67.0%) and melanoma ≤ 1 mm thick (65.1%; Table 1).

Overall QoL (EQ-5D-5L)

A greater proportion of melanoma survivors reported problems with anxiety or depression compared with the general population (30.7% vs 21.6%; $p < 0.01$), and anxiety and depression was the most prevalent problem experienced by participants at 1, 3 and 5 years (Table 2). A greater proportion of melanoma survivors 3 years post-diagnosis experienced difficulties with usual activities compared to the general population (24.6% vs 14.8%; $p < 0.05$), although there were no statistically significant differences for this domain for the 1 year, 5 year or combined groups. The proportions of survivors reporting problems with other QoL domains of mobility, personal care and pain or discomfort were similar compared to the general population.

Symptoms

FCR was the most common self-reported symptom across all time points, with 53.2%, 43.5% and 48.1% of participants reporting this symptom at 1, 3 and 5 years (Table 2). Fear of cancer spreading was also reported (42.0%, 32.9% and 38.4% at 1, 3 and 5 years). Approximately 20–30% of participants reported fear of dying, memory loss, trouble sleeping and always feeling tired at each time point. Approximately 15–20% reported problems with concentration, mood swings, irritability, feeling they were to blame for their melanoma, and feeling anxious about moles and changes to their skin.

Unmet information needs

At 1, 3 and 5 years, 59.8%, 48.1% and 59.6% of participants, respectively, reported having all the melanoma-related information they needed, leaving 40–50% of participants with some form of unmet information need (Table 2). The most frequently endorsed needs related to psychological and emotional aspects of living with cancer, which remained high in the 5 year cohort (20.6%), and physical aspects of living with cancer. The need for information on diet and lifestyle was high at 1 year (13.9%) and was lower in the 3 year (10.8%) and 5 year (6.3%) groups.

Variables associated with QoL (EQ-5D-5L)

Lower EQ-5D-5L scores were associated with living in a nursing home (-0.539 , $p < 0.001$, relative to those who live with their partner, spouse, family or friends) and having another long-standing health condition (-0.444 , $p < 0.01$, relative to those who do not). Other factors, including having melanoma that recurred (standardised coefficient of -0.194 , $p < 0.01$, relative to those whose cancer had fully responded to treatment,) or participants not knowing what

was happening with their melanoma (-0.096 , $p < 0.01$, relative to those whose cancer had fully responded to treatment), and melanoma > 2 mm thick at diagnosis (-0.06 , $p < 0.05$, relative to those with a melanoma < 1 mm thick) were negatively associated with QoL; however, these factors warrant further exploration due to the small effect sizes. Sex and age were not found to impact on QoL in this study.

Discussion

This study highlights the significant psychological burden experienced by melanoma survivors compared to the general population. Anxiety and depression as assessed on a single QoL item were commonly reported and similar to previously reported rates of psychological distress [5]. Fear of cancer recurrence was the most commonly self-reported symptom across all time points, consistent with previous studies [4, 12]. Around half of survivors at each time point reported FCR despite the fact that the majority of participants (65.1%) had a melanoma less than 1 mm thick, which portends an overall good prognosis. Substantial proportions of participants (20–30% at years 1, 3 and 5) also reported fear of cancer spreading, fear of dying, memory loss and sleeping difficulties, and approximately one in five participants reported unmet needs for information regarding the psychological and emotional aspects of living with cancer, which persisted 5 years from diagnosis. Other studies have similarly found that people affected by melanoma frequently report desire for honest and clear information about melanoma from healthcare professionals [12, 13].

Despite these results, the psychological needs of melanoma survivors are often overlooked due to the relatively straightforward treatment and good prognosis associated with early stage disease. These findings highlight the need to screen for psychological distress, and provide evidence-based educational resources and psychological interventions to better support patients [14]. Previous studies have reported brief psychological interventions which reduce fear of cancer recurrence and psychological stress, as well as improve melanoma knowledge at both one and 6 months' post-intervention [15]. Our findings also reinforce the importance of surveillance, not only as a means of detecting melanoma recurrence, but also a means of reassuring patients that recurrences will be detected and treated early which may help to mitigate fear of cancer recurrence and provide a sense of safety and control [16].

Melanoma survivors in this study reported difficulties across QoL domains of mobility, personal care, and pain in similar proportions compared with the general population; similar QoL outcomes for melanoma survivors compared with people without a history of melanoma have likewise been observed in previous studies [17, 18]. Participants

Table 1 Characteristics of respondents and non-respondents

Characteristic	Respondents (%)				Non-respondents (%)	Eligible (%)
	All	1 year	3 years	5 years	All	All
Age						
< 40	9.0	10.7	6.0	9.4	13.3	11.3
40–49	13.2	8.3	14.3	19.6	17.0	15.2
50–59	22.9	20.5	21.1	28.3	17.7	20.1
60–69	29.0	33.2	27.8	23.9	23.0	25.8
70–79	16.8	14.1	23.3	14.5	15.7	16.2
> 79	9.0	13.2	7.5	4.3	13.3	11.3
Sex						
Male	49.8	50.7	45.9	52.2	54.2	52.1
Female	50.2	49.3	54.1	47.8	45.8	47.9
Thickness						
< 1 mm	65.1	60.5	66.9	70.3	67.2	66.2
1.01–2 mm	21.6	24.9	20.3	18.1	19.5	20.5
2.01–3 mm	6.9	7.3	8.3	5.1	5.7	6.3
3.01–4 mm	0.8	2.0	0.0	0.0	2.2	1.6
> 4 mm	5.3	4.9	4.5	6.5	5.3	5.3
Unknown	0.2	0.5	0.0	0.0	0.2	0.2
Morphology						
Superficial spreading melanoma	67.0	68.8	59.4	71.7		
Malignant melanoma, NOS	21.2	19.5	27.8	17.4		
Lentigo maligna melanoma	9.2	8.3	12.0	8.0		
Acral lentiginous melanoma	0.6	1.5	0.0	0.0		
Nodular melanoma	0.2	0.5	0.0	0.0		
Other	1.7	1.5	0.8	2.9		
Clark level						
2	41.4	39.0	43.6	42.8		
3	23.7	21.5	22.6	28.3		
4	31.5	37.1	30.8	23.9		
5	3.4	2.4	3.0	5.1		
Response to treatment						
Has responded fully to treatment	86.5	82.4	85.7	93.4		
Has been treated but is still present	1.7	1.5	2.3	1.5		
Has not been treated	0.6	1.0	0.8	0.0		
Has come back after treatment	1.7	2.0	2.3	0.7		
Not certain what is happening	6.1	9.3	3.8	3.7		
Not stated	3.4	3.9	5.3	0.7		
Other long-standing health condition						
Yes	46.0	44.4	45.9	48.6		
No	47.7	49.3	44.4	48.6		
Not stated	6.3	6.3	9.8	2.9		
Living arrangements						
Live with partner, spouse, family or friends	75.7	77.1	75.9	73.5		
Live alone	18.4	17.6	15.0	22.8		
Live in a nursing home	1.1	1.0	1.5	0.7		
Other	1.3	1.0	1.5	1.5		
Not stated	3.6	3.4	6.0	1.5		
Total cases (<i>n</i>)	476	205	133	138	548	1024

NOS not otherwise specified

Table 2 (a) Weighted percentages of melanoma survivors reporting problems with EQ-5D-5L items, (b) Weighted percentage of melanoma survivors reporting “strongly agree” or “agree” with symptom items, and (c) Percentage of melanoma survivors reporting desire for more information

	General population	Melanoma survivors (%)			
		ALL	1 year	3 years	5 years
(a) EQ-5D-5L items					
Mobility	16.6	19.3	15.5	22.9	20.4
Personal care	4.5	4.3	3.7	3.1	5.9
Usual activities	14.8	19.3	17.9	24.6*	16.1
Pain or discomfort	32.2	26.9	30.4	25.0	24.6
Anxiety or depression	21.6	30.7**	30.0*	30.7*	31.4*
(b) Self-reported symptoms					
Fear of cancer recurrence		48.3	53.2	43.5	48.1
Fear of cancer spreading		37.8	42.0	32.9	38.4
Fear of dying		23.2	26.1	22.4	21.2
Memory loss		22.6	22.4	24.8	20.6
Trouble sleeping		28.9	24.8	29.8	32.2
Trouble concentrating		18.8	16.4	17.3	22.6
Always tired		22.1	20.2	19.7	26.5
Mood swings		19.3	22.4	17.5	18.1
Often irritable		16.6	19.1	16.5	14.3
Blame for melanoma		18.7	17.5	18.8	19.7
Anxious about checking for moles/skin for changes		17.0	17.8	16.9	16.3
(c) Information needs					
Diet and lifestyle		10.5	13.9	10.8	6.3
Physical activity and exercise		7.7	7.6	11.3	4.5
Financial help or benefits		5.4	5.0	6.3	5.1
Cost of prescriptions		2.4	2.5	3.8	1.2
Returning to or staying in work		2.9	2.2	4.6	2.2
Information/advice for family/friends/carer		6.6	6.0	7.9	6.1
Information about support groups		6.9	5.7	6.4	8.7
Pain management and control		4.8	4.7	5.9	4.1
The physical aspects of living with and after cancer		16.3	15.8	19.2	14.2
The psychological or emotional aspects of living with and after cancer		18.8	19.4	16.1	20.6
I have all the information and advice I need		56.3	59.8	48.1	59.6

** $p < 0.01$, * $p < 0.05$

however reported high unmet information needs regarding the physical aspects of living with and after cancer, indicating the potential for melanoma survivors to experience sustained morbidity following surgery. Incorporating physiotherapy and lymphoedema services into routine post-treatment care may help address this.

Information needs regarding diet and lifestyle were also high 1 year post-diagnosis, but lower at 5 years. This may

be related to the time needed to adjust, psychologically as well as practically, to the diagnosis of melanoma, as well as concerns regarding fear of recurrence and fear of the cancer spreading, which were highest during the first year after diagnosis. Receiving a diagnosis of melanoma may therefore be a useful ‘teachable moment’ to reinforce lifestyle advice regarding sun exposure, in the hope of reducing the risk of subsequent primaries, particularly for younger patients [19].

Several factors were associated with reduced QoL in melanoma survivors, including living in a nursing home and concomitant chronic health issues, which are consistent with similar studies of cancer survivors [7]. Those with a tumour > 2 mm in thickness at diagnosis were also more likely to report reduced QoL, possibly due to the increased psychological burden associated with a higher risk of recurrence and disease requiring more invasive and burdensome treatments such as lymph node dissection. Awareness of risk factors associated with lower QoL in melanoma survivors may assist with identifying those who require additional support, as well as inform risk-based models of care.

Study limitations

The response rate achieved in this study was equivalent to similar Australian studies of patient experiences and outcomes [20, 21]; however, it was lower than that achieved by other countries [6]. This was a cross-sectional study recruiting three separate cohorts 1, 3 and 5 years following initial melanoma diagnosis, rather than a longitudinal study; thus, differences between 1, 3 and 5 year cohorts should be interpreted with caution. As this study was conducted in 2014, presented data at time of publication are 6 years old.

Opportunities for future research

Future studies should collect prospective data on a single cohort of melanoma patients and follow participants longitudinally to understand patient experiences across time. Further work is also required to identify the clinical, psychological and social determinants of reduced QoL following a melanoma diagnosis, particularly those factors that may contribute to stratification into different models of follow-up care, or those that may be modified by interventions [22].

Conclusion

A substantial proportion of people who have had melanoma report anxiety, depression, and fear of cancer recurrence or spreading up to 5 years post-diagnosis. Patients also report unmet information needs regarding the psychological and physical aspects of life after cancer, which may persist for years after diagnosis. Understanding the specific challenges experienced by people who have had melanoma will allow us to more precisely screen for and detect these difficulties in advance. This population may benefit from more information as well as interventions to address these difficulties.

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Compliance with ethical standards:

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

Ethical approval Ethics approval was granted by the Cancer Council Victoria Human Research Ethics Committee (Project No: HREC 1307). All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed consent All participants included in the study were provided with details regarding the study and informed that return of the completed study implied their consent to participate in the study.

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