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**Title:** Variations in supportive care needs of patients after diagnosis of localised cutaneous melanoma: a 2-year follow-up study

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The authors have declared no conflicts of interest.

**Abstract**

**Purpose:** We aimed to describe variations in unmet supportive care needs of patients diagnosed with localised melanoma at high risk of recurrence, and factors associated with initial and persisting moderate-to-high needs.

**Methods:** We ascertained386 patients diagnosed with clinical stage IB-II melanoma and administered 6-monthly surveys for 2 years. The proportion experiencing at least one moderate-to-high need was assessed among salient subgroups: 306 patients with no previous melanoma and 80 with previous melanoma at enrolment; 30 who experienced disease recurrence during follow-up and 31 who developed another primary. Baseline factors associated with (a) needs at enrolment and (b) persistent needs over 2 years (or as long as disease-free) were identified by logistic regression analyses.

**Results:** The proportion of patients with needs substantially declined over the first 6 months (if no previous melanoma, from 48% to 22%, p<0.001; previous melanoma, 35% to 17%, p=0.007) and in those remaining disease-free, needs declined further by 24 months (to 14% and 6% respectively). By contrast 50% of those experiencing recurrence, and 39% of those who developed another primary, reported needs. Stressful life events and anxiety were associated with needs at enrolment. At least 1 need, mainly fear of recurrence, persisted in 22% of disease-free participants. Persistent needs were predicted by age, depression, anxiety and other stressful life events.

**Conclusions:** Melanoma patients’ needs peak when first diagnosed and if disease recurs. Younger people or those experiencing additional stressful events, anxiety or depression are more likely to experience persistent needs and may benefit from tailored support.

**Keywords:** Localised melanoma, supportive care needs, anxiety, depression, longitudinal study

**Introduction**

Cutaneous melanoma is a high incidence cancer in white populations [[1](#_ENREF_1), [2](#_ENREF_2)]. Although patients diagnosed with a thin localised primary cancer generally have an excellent prognosis [[3](#_ENREF_3)], those with a localised invasive melanoma >1mm in thickness have a 10% risk of recurrence within 18 months [[4](#_ENREF_4)]. To date, despite major progress in therapy of advanced disease, metastatic melanoma remains irremediably fatal. This combination of high incidence combined with potential fatality of invasive disease is unique. In addition to the demands common to all cancer patients, people diagnosed with a high-risk primary melanoma face the dual possibility of recurrence or development of a second primary melanoma. Patient-centred care is the benchmark of quality cancer care [[5](#_ENREF_5)], therefore it is imperative that we understand how these patients’ dual risks and subsequent disease-related events affect their supportive care needs so that health-care providers can deliver appropriate, responsive care over the disease continuum.

Supportive care needs assessment tools directly measure the gap between a person’s experience of support and their stated desire for some further action or resource [[6](#_ENREF_6)]. Longitudinal assessment of needs enables us to determine if needs are met over time by available support mechanisms or if there are deficiencies in service delivery so that needs persist. Moreover, longitudinal assessment is able to track patterns of needs that occur with subsequent disease-related events. To date however, the supportive care needs of people diagnosed with invasive melanoma have been assessed only through small qualitative studies of selected groups [[7](#_ENREF_7), [8](#_ENREF_8)] or in cross-sectional studies combining patients diagnosed very recently (3 months) and up to 5 years [[9](#_ENREF_9), [10](#_ENREF_10)] or more [[11-13](#_ENREF_11)] previously. Moreover past studies have pooled patients with localised or metastatic disease. There is no information on the supportive care needs of patients at, or after, diagnosis of high-risk primary melanoma and no information about their needs when disease recurrence occurs.

In 2010 we initiated a longitudinal study of patients with locally invasive melanoma at high risk of recurrence and showed that at the time of diagnosis 1/3 to 1/4 reported moderate-to-high unmet needs in regard to melanoma-specific information and psychological concerns [[14](#_ENREF_14)]. The aim of the present study was to assess the proportion of these high-risk primary melanoma patients who report unmet supportive care needs over the first 2 years after diagnosis, taking account of any history of previous primary melanoma, as well as the level of needs following melanoma recurrence or diagnosis of a subsequent new primary. We also studied factors associated with initial unmet needs and with persistent needs over the 2 year follow-up period.

**Methods**

***Participants and procedures***

The study was approved by all relevant institutional ethics committees. Informed consent was obtained from all individual participants included in the study. Patients diagnosed with a primary cutaneous melanoma stage IB or II between October 2010 and May 2013 were ascertained from 3 urban and 2 regional hospitals, through 5 associated melanoma surgeons, and 3 private pathology companies in Queensland, Australia [[14](#_ENREF_14)]. Patients were excluded if aged under 16; physically or mentally unable to complete a written questionnaire, if they did not complete the initial questionnaire within 2.5 months of definitive surgery or if they had a sentinel lymph node biopsy showing nodal spread of microscopic disease. Questionnaires were then mailed 6-monthly for 2 years or until participants died, withdrew or were otherwise lost to follow-up.

***Outcome measures***

*Supportive care needs* were assessed using the Supportive Care Needs Survey-Short Form (SCNS-SF34) [[15](#_ENREF_15)] and its melanoma-specific module.[[16](#_ENREF_16)] The SCNS-SF34 has 34 items in 5 domains: psychological (10 items); physical and daily living (5 items); health system and information (11 items); patient care and support (5 items); and sexuality (3 items). In the development sample of 444 mixed cancer patients, these items were shown to collectively account for 73% of the variance and Cronbach alpha scores for the domains ranged from 0.86 to 0.96 [[15](#_ENREF_15)]. The melanoma-specific module contains 12 additional items. Participants rated their need for help with each item over the past month as: 1 = not applicable (no need), 2 = satisfied (need met), 3 = low unmet need, 4 = moderate unmet need, 5 = high unmet need. Dichotomous need domain scores classified as no-to-low need versus at least 1 moderate-to-high need [[16](#_ENREF_16)] (a) at baseline and (b) persistent where at least 1 moderate-to-high need was present at baseline and at least 1 subsequent time-point, were used as they distinguish the clinical threshold when supportive care provision is required.

***Factors of interest***

*Demographic factors* including age, sex, relationship status and education level were self-reported. Postcode standards were used to classify remoteness of place of residence [[17](#_ENREF_17)].

*Personal health and service use* were self-reported. General health (rated as excellent, very good, good, fair or poor), presence of any of 10 comorbidities (any, none) and the frequency of skin checks were assessed. Hospital Anxiety and Depression Scale (HADS) used 14 items to distinguish the 2 sub-scales (Cronbach alphas of 0.93 and 0.90, respectively) with recommended scoring cut-offs of “non-case” (0-7), “doubtful case” (8-10), and “case” (11-21) [[18](#_ENREF_18)]. Participants reported if stressful life events or medical conditions apart from melanoma had affected their quality of life (response range: not at all to very much or not applicable). Use of any of 22 supportive care services for melanoma (such as cancer helplines; counselling or community-based support group) was ascertained (any service use, none).

*Clinical details* of index primary melanomas were extracted from histopathology reports including site; histological classification; thickness (mm); who performed definitive surgery (general practitioner; specialist), and whether sentinel lymph node biopsy had been performed. All reports of melanoma prior to the present study were histologically confirmed, as were all melanoma recurrences (defined as any spread of disease after definitive surgery of the primary melanoma) and any new primaries during follow-up.

***Statistical analysis***

Intermittent missing data were conservatively imputed as no unmet needs unless the patient had moderate-to-high unmet needs at both the prior and subsequent data points in which case the last observation was carried forward. Thus the longitudinal dataset contained monotone missing only. Data collected from patients after disease recurrence or diagnosis of a new primary were analysed separately and treated as monotone missing after the disease event in the longitudinal analysis of needs among patients who were disease-free.

To gauge the influence of attrition (monotone missing) on sample representativeness we created an attrition status variable (complete disease-free follow-up; withdrew or did not respond (thus potentially missing completely at random); experienced an adverse event (recurrence, new primary, too sick or died, thus missing not at random). We plotted the proportion of patients with moderate-to-high unmet needs at each time-point by attrition status. To determine factors associated with attrition[[19](#_ENREF_19)] we cross-tabulated baseline characteristic against attrition status.

McNemar tests were used to determine if the proportion of people reporting moderate-to-high unmet needs between each time-point were significantly different (e.g. baseline versus 6 months).

Factors of interest were tested for multicollinearity but none was found. We used Chi-squared tests to assess bi-variable associations between factors and having moderate-to-high unmet total, melanoma-specific or psychological needs (a) at baseline and (b) persistent during follow-up. Analyses of baseline needs in relation to type of doctor performing surgery and whether sentinel lymph node was biopsied were restricted to the subgroup of 231 patients who completed their baseline questionnaire after definitive surgery. Participants reporting moderate-to-high unmet need(s) at baseline and at least 1 follow-up point (i.e. persistent needs) were considered the most salient for supportive care intervention, and multivariable logistic regression models were considered the optimal approach for characterising associated factors. Factors that were statistically significant at bivariable analyses (p<0.1) were included in multivariable logistic regression models. Those associated with unmet supportive care needs in (a) any, or the highest prevalent (b) melanoma-specific or (c) psychological domains were assessed. Variables non-significant across all multivariable models were removed.

**Results**

***Participants***

The 386 patients recruited for study had a mean age of 61 years, 212 (55%) were men (same age and sex distributions as in the population-based Queensland Cancer Registry),[[14](#_ENREF_14)] 270 (70%) had primary tumours ≤2mm thick and 80 (21%) had a previous melanoma (Table 1).Of the 386, 260 (67%) (211 without and 49 with a previous history of melanoma at study enrolment) completed 24 months of follow-up and remained disease-free (Figure 1). Overall 61 patients (16%) had a recurrence and/or subsequent new primary melanoma comprising 34 (9%) with disease recurrence and an overlapping 47 (12%) who developed new primary melanoma, leaving 325 (84%) disease-free at 2 years. A further 65 (17%) patients were lost to follow-up (55 withdrew or did not respond to multiple follow-up attempts; 10 died or were too sick to respond). The loss to follow-up rate was low with 18 (5%), 16 (4%), 9 (2%) and 22 (6%) patients lost at the 6, 12, 18 and 24 month follow-ups respectively (Figure 1). Patients who experienced another disease event during follow-up were significantly older or less educated than those patients with complete follow-up who remained disease-free (Table 1). On the other hand, those who withdrew were more likely to be recruited into the study via a specialist practice compared to those with complete follow-up (Table 1).

***Unmet needs over time and with disease-events***

For patients diagnosed with a first primary melanoma the proportion who reported at least 1 moderate-to-high unmet need dropped significantly from 48% (n=148/306) at baseline to 22% (n=62/286) at the 6-month follow-up (p<0.001) and then steadily declined to 14% (n=30/211) at the 24-month follow-up (p=0.150) (Figure 2). At all time-points the proportion of patients with unmet needs was lower in patients who had a confirmed history of melanoma prior to study enrolment (35% n=28/80 at baseline; 17% n=12/69 at 6-month follow-up and; 6% n=3/49 at 24 month-follow-up) compared to those without, although the difference between the two groups was statistically significant only at baseline. The point prevalence of at least 1 moderate-to-high unmet need when melanoma recurred was 50% (n=15), very similar to the 48% (n=148) prevalence when the first primary melanoma had been diagnosed. However, when patients were diagnosed with a subsequent new primary melanoma the prevalence of at least 1 moderate-to-high unmet need was lower at 39% (n=12).

The prevalence of need domains and individual need items at baseline has been previously reported [[14](#_ENREF_14)]. Five of the 6 need domains followed the same trajectory as total needs and significantly (p<0.05) contributed to the reduction in needs in the first 6 months. Only sexuality needs started and remained low. Almost 1/4 (22%, n=83) of disease-free patients had at least 1 persistent moderate-to-high unmet need; 14% (n=52) of these were in the melanoma-specific domain and 12% (n=47) in the psychological domain. Overall 275 separate counts of a moderate-to-high unmet need were reported between 6 and 24 months after baseline among the 83 disease-free people with persistent needs. The top five were needing help with fears about the cancer spreading (59 counts), uncertainty about the future (50 counts), more information about the risk of recurrence of melanoma (49 counts), more information about possible outcomes when melanoma has spread from the skin (40 counts) and, to be informed about how and when to check skin for changes (38 counts). Additionally, 8% (n=30) of patients reported no needs at baseline but a new moderate-to-high unmet need at follow-up. The total count of new moderate-to-high unmet needs among these 30 patients was 109 with the top items being a need for help with lack of energy/tiredness (11 counts) and concerns about the worries of those close to you (10 counts). Of the 30 patients with new needs, 19 reported another stressful life event that affected their quality of life somewhat to very much during follow-up, leaving 11 patients solely with new melanoma-related needs.

***Factors associated with moderate-to-high unmet need***

At bivariable analysis no significant associations were found between reporting (a) baseline or (b) persistent moderate-to-high unmet needs and marital status, remoteness of residence, ascertainment source, tumour site, histological classification, who performed definitive surgery, whether sentinel lymph node biopsy was performed, having a comorbidity or frequency of skin checks (data not shown). Sex, education level, tumour thickness and general health became non-significantly associated with both initial and persistent unmet total, melanoma-specific or psychological needs after adjustment. In the multivariable analyses people with previous history of melanoma at baseline had significantly lower odds of any needs and melanoma-specific needs at baseline (Table 2). For any needs, it was patients who reported other stressful life events, were anxious or had used cancer support services were significantly more likely to have moderate-to-high unmet needs at baseline while depression and other stressful life events predicted having persistent moderate-to-high unmet needs among patients who remained disease-free (Table 2). Most associations between baseline risk factors and total needs (baseline and persistent) were also observed when looking specifically at the melanoma and psychological needs domains (Table 2). Additionally, patients younger than 60 years were more likely to have persistent moderate-to-high unmet melanoma-specific needs and patients who were anxious or had used cancer support services were significantly more likely to have persistent moderate-to-high unmet psychological needs. All associations did not change significantly when those with a previous history of melanoma were excluded (data not shown).

***Characterising missingness***

Participants with complete follow-up had a similar proportion (45%; n=118/260) of unmet needs at baseline to those who later withdrew or did not respond (45%; n=25/55) or who later had an adverse event (46%; n=33/71) (Figure 3). However, the proportion with unmet needs was higher at the 6-, 12- and 18-month follow-ups among the latter groups (withdrew or did not respond: 32%; n=13/41, 31%; n=8/26, 26%; n=5/19 and had adverse event: 26%; n=14/54, 31%; n=9/29, 24%; n=4/17 respectively) compared to those with complete follow-up (18%; n=47/260, 15%; n=40/260, 16%; n=41/260 respectively) (Figure 3).

**Discussion**

This study is novel and important because it provides formal longitudinal assessment of supportive care needs of patients with primary invasive melanoma at high risk of recurrence. Such assessment provides the evidence base required for establishing a program of support for those identified as having high and/or persistent needs following a diagnosis of high-risk melanoma. We show that while half these patients had at least 1 moderate-to-high need when first diagnosed, these were mostly adequately addressed within 6 months. When patients were diagnosed with a recurrence, half experienced another spike in needs. In contrast only around a third of patients who had a previous primary melanoma had unmet needs. A major finding was that 1 in 5 high-risk primary melanoma patients had persistent needs in the 2 years after their diagnosis; these people were characterised at diagnosis as having experienced other stressful life events or high levels of anxiety or depression and for melanoma-specific needs, being aged less than 60 years. Their persistent needs were in the psychological and melanoma-specific domains and focused around fear of recurrence, possible outcomes if their melanoma spread and the need for more information about their risk of recurrence and about checking their skin for changes. Almost all of the needs in the physical/daily living, health system/general information, patient care and sexuality domains that were applicable to this population were satisfied over time.

Compared with patients treated for other solid cancers, the level of supportive care needs in melanoma patients is lower. For example among newly diagnosed patients the top moderate-to-high need was reported by 17% of our sample [[14](#_ENREF_14)] versus 73% of women receiving treatment for breast cancer [[20](#_ENREF_20)] and 27% of people within 6 months of diagnosis with any solid tumour [[21](#_ENREF_21)]. Compared with cross-sectional studies, prospective studies commonly find lower rates of distress and symptom burden, highlighting the importance of careful longitudinal assessment for planning clinical care [[22](#_ENREF_22)]. In addition to initially lower levels of supportive care needs, we observed a significant decrease in the proportion of patients with unmet needs over time. This is in contrast to other longitudinal studies which have reported a stable trajectory of unmet physical and psychological needs over the first 6 [[23](#_ENREF_23)], 8 [[24](#_ENREF_24)] or 24 months [[25](#_ENREF_25)] after treatment for a solid tumour, breast or ovarian cancer, respectively. However, these studies commonly recruited participants at the end of adjuvant treatment, so prognoses were poorer, perhaps explaining their sustained support needs but also making direct comparison with our results difficult. Similar to our findings, these studies found that distress [[23](#_ENREF_23), [25](#_ENREF_25)] and other stressful life events [[23](#_ENREF_23)] were risk factors for persistent unmet needs and that disease recurrence (as reflected by the surrogate variable of renewed chemotherapy of solid cancers) was associated with elevated unmet needs [[25](#_ENREF_25)].

Melanoma patients who had used support services reported higher initial and persistent unmet psychological needs, but we are unable to say whether patients were triaged to the appropriate psychological support or whether using such services heightened their distress. Dissatisfaction with follow-up care coordination may also play a part. An Australian study of 64 patients diagnosed with primary melanoma in the previous year indicated that 52% of participants were not satisfied with their support and would have liked more information and a care coordinator [[26](#_ENREF_26)].

Distress has recently been recognised as the 6th vital sign in cancer care [[27](#_ENREF_27)]. Carlson [[28](#_ENREF_28)] concluded that screening for distress and unmet needs facilitates communication around emotional complications and in conjunction with evidence-based treatment has the potential to significantly improve quality of life. This supports our findings that distress is an important factor contributing to unmet supportive care needs for people with melanoma. We have shown there is potentially room for improvement in the care of high-risk primary melanoma patients with 12% in our study reporting persistent unresolved psychological concerns, supporting the evaluation of psycho-educational intervention for reducing fear of new or recurrent melanoma [[29](#_ENREF_29)]. Specifically among cancer patients diagnosed with early-stage disease, satisfaction with information provision is correlated with reduced fear of recurrence [[30](#_ENREF_30)], thus the provision of individualised risk prediction information and specific advice about how and when to check skin for changes may alleviate some psychological morbidity in this group.

Our multi-centre longitudinal study had a large sample size and low rate of loss to follow-up. Thus we believe our estimates are largely unbiased by dropout and generalizable to most patients with high-risk primary melanoma. If anything, we may have underestimated supportive care needs during follow-up as imputation of intermittent missing data was conservative and those with monotone missing data had higher needs at available follow-up assessments.

Post-treatment follow-up is an important component of cancer care [[31](#_ENREF_31)]. Follow-up is typically recommended at 3- to 6-monthly intervals for 5 years for patients with stage I and stage II melanoma, and yearly thereafter [[32](#_ENREF_32)]. Although in many countries dermatologists provide a large component of the follow-up care for melanoma patients, in high-risk populations like Australia, follow-up may be with a surgeon, dermatologist, or general practitioner who may or may not have additional training in skin cancer management, or with a combination of doctors. Our study found that in Queensland the unmet needs of the growing number of patients with clinical stage IB or II melanoma are likely to be low shortly after primary treatment. Some of these needs may have naturally subsided with time, while others would have been met by successful follow-up care. Post-treatment screening for distress and other stressful life events is recommended to identify those patients with high probability of having persistent needs. Additional psychological support and assessment of whether such support alleviates their specific persisting needs is required. Heightened consideration of younger patients (aged less than 60) for persistent melanoma-specific needs is also advised. Furthermore, as may be expected, patients who experience a recurrence have an immediate rise in supportive care needs. Further understanding of these specific needs and whether they are being met is called for.

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|  |
| --- |
| Primary Melanoma Project – Patient Reported Outcome Study  Participants enrolled between October 2010 and May 2013: n = 386  Previous history of melanoma: No = 306; Yes = 80 |

Lost to follow-up n=18

* Withdrew = 7
* Non-response = 7
* Too sick = 2
* Died = 2

Subsequent diseasea n= 13

* Recurrence = 7
* New melanoma = 6

failed to complete this survey but are still enrolled and have not yet been sent the next questionnaire

|  |
| --- |
| 6-months follow-up  Participants in the longitudinal analysis: n =355 (92%)  Previous history of melanoma: No = 286; Yes = 69  Of these: 28 (8%) had intermittent missing data |

Lost to follow-up n=16

* Withdrew = 4
* Non-response = 11
* Died = 1

Accumulated subsequent diseasea n= 37

* Recurrence = 20
* New melanoma = 17

|  |
| --- |
| 12-months follow-up  Participants in the longitudinal analysis: n =315 (82%)  Previous history of melanoma: No = 255; Yes = 60  Of these: 32 (10%) had intermittent missing data |

Lost to follow-up n=9

* Withdrew = 4
* Non-response = 3
* Too sick = 2

Accumulated subsequent diseasea n= 47

* Recurrence = 25
* New melanoma = 22

|  |
| --- |
| 18-months follow-up  Participants in the longitudinal analysis: n =296 (77%)  Previous history of melanoma: No = 238; Yes = 58  Of these: 27 (9%) had intermittent missing data |

Lost to follow-up n=22

* Withdrew = 4
* Non-response = 15
* Too sick = 2
* Died = 1

Accumulated subsequent diseasea n= 61

* Recurrence = 30
* New melanoma = 31

|  |
| --- |
| 24-months follow-up  Participants in the longitudinal analysis: n =260 (67%)  Previous history of melanoma: No = 211; Yes = 49  Of these: 13 (5%) had intermittent missing data |

**Figure 1. Flow of participants contributing to longitudinal disease-free analyses and analyses following recurrence or new primary melanoma**

a Only first subsequent disease event counted (some participants had multiple events within the follow-up period). Participants (n=15) who had a simultaneous recurrence and new melanoma were counted as having a recurrence i.e. the more severe event.

**Figure 2: Proportion of patients who reported at least 1 moderate-to-high unmet supportive care need over time by history of previous melanoma and point prevalence following a recurrence or subsequent new primary melanoma.**

**Figure 3. Percent of people experiencing moderate-to-high unmet needs by attrition status.**

**Table 1: Baseline characteristics overall and by attrition status**

|  |  |  | **Reason for monotone missing in the longitudinal analysis** | | | |
| --- | --- | --- | --- | --- | --- | --- |
| Total sample n=386 | Complete disease-free follow-up  n=260 | Adverse event (recurrence, new primary, too sick or died) n=71 | | Withdrew or did not respond n=55 | |
| **%** | **n(%)** | **n(%)** | **p-value1** | **n(%)** | **p-value1** |
| **Age (years)** |  |  |  |  |  |  |
| ≤59 | 38 | 100(38) | 20(28) | 0.010 | 27(49) | 0.285 |
| 60-69 | 30 | 85(33) | 17(24) |  | 13(24) |  |
| 70+ | 32 | 75(29) | 34(48) |  | 15(27) |  |
| **Sex** |  |  |  |  |  |  |
| Male | 55 | 137(53) | 45(63) | 0.109 | 30(55) | 0.803 |
| Female | 45 | 123(47) | 26(37) |  | 25(45) |  |
| **Relationship status** |  |  |  |  |  |  |
| Partner | 74 | 195(75) | 54(76) | 0.894 | 38(69) | 0.340 |
| No partner | 25 | 64(25) | 17(24) |  | 17(31) |  |
| **Level of education** |  |  |  |  |  |  |
| University/college | 22 | 63(24) | 15(21) | 0.009 | 8(15) | 0.263 |
| Senior school/diploma/trade | 39 | 108(42) | 18(25) |  | 24(44) |  |
| Junior school | 39 | 89(34) | 38(54) |  | 23(42) |  |
| **Previous Melanoma** |  |  |  |  |  |  |
| No | 79 | 211(81) | 51(72) | 0.087 | 44(80) | 0.843 |
| Yes | 21 | 49(19) | 20(28) |  | 11(20) |  |
| **Thickness of primary** |  |  |  |  |  |  |
| 1.0mm-2.0mm | 70 | 179(69) | 51(72) | 0.659 | 40(73) | 0.596 |
| >2.00mm | 30 | 80(31) | 20(28) |  | 15(27) |  |
| **Primary site** |  |  |  |  |  |  |
| Head/Neck | 20 | 48(18) | 21(30) | 0.242 | 9(16) | 0.077 |
| Trunk | 36 | 95(37) | 22(31) |  | 21(38) |  |
| Upper Limb | 21 | 51(20) | 12(17) |  | 18(33) |  |
| Lower Limb | 23 | 66(25) | 16(23) |  | 7(13) |  |
| **Histological type** |  |  |  |  |  |  |
| SSM | 43 | 107(44) | 26(41) | 0.933 | 22(44) | 0.934 |
| Nodular | 22 | 54(22) | 14(22) |  | 12(24) |  |
| Other | 34 | 84(34) | 23(37) |  | 16(32) |  |
| **Sentinel lymph node biopsy** |  |  |  |  |  |  |
| Not done | 67 | 173(67) | 52(73) | 0.284 | 33(60) | 0.354 |
| Done | 33 | 87(33) | 19(27) |  | 22(40) |  |
| **Ascertainment source** |  |  |  |  |  |  |
| Public hospital | 54 | 146(56) | 37(52) | 0.800 | 25(45) | 0.044 |
| Specialist practice | 30 | 70(27) | 20(28) |  | 24(44) |  |
| Pathology laboratories | 17 | 44(17) | 14(20) |  | 6(11) |  |
| **Dr performing definitive surgery** |  |  |  |  |  |  |
| GP and skin cancer clinic | 10 | 29(11) | 6(8) | 0.698 | 5(9) | 0.438 |
| Specialist | 89 | 230(88) | 65(92) |  | 49(89) |  |
| Did not have definitive surgery | 1 | 1(0) | 0(0) |  | 1(2) |  |

Testing difference between complete follow-up group to withdrawal group via chi-squared analysis

**Table 2.** Baseline risk factors for reporting at least 1 moderate-to-high unmet need at (a) baseline and (b) baseline and follow-up (persistenta)

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | **Total (any) needs** | | | | |  | **Melanoma-specific needs** | | | | |  | **Psychological needs** | | | | |
|  | Baseline  (n=176/ 386) | |  | Persistent  (n=83/376)b | |  | Baseline  (n=123/386) | |  | Persistent  (n=52/382)c | |  | Baseline  (n=96/386) | |  | Persistent  (n=47/382)c | |
|  | Odds ratio |  |  | Odds ratio |  |  | Odds ratio |  |  | Odds ratio |  |  | Odds ratio |  |  | Odds ratio |  |
| (95% confidence interval) | p-value | (95% confidence interval) | p-value |  | (95% confidence interval) | p-value |  | (95% confidence interval) | p-value |  | (95% confidence interval) | p-value |  | (95% confidence interval) | p-value |
| Previous Melanoma |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| Yes | 0.5(0.3-1.0) | 0.032 |  | 0.6(0.3-1.3) | 0.186 |  | 0.5(0.3-1.0) | 0.041 |  | 0.6(0.3-1.5) | 0.292 |  | 0.7(0.4-1.5) | 0.395 |  | 0.8(0.3-1.9) | 0.546 |
| No | Referent |  |  | Referent |  |  | Referent |  |  | Referent |  |  | Referent |  |  | Referent |  |
| Age (years) |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| ≤59 | 1.5(0.8-2.5) | 0.302 |  | 1.7(0.9-3.3) | 0.280 |  | 1.7(1.0-3.0) | 0.108 |  | 2.4(1.1-5.4) | 0.013 |  | 1.7(0.9-3.3) | 0.232 |  | 1.7(0.7-4.4) | 0.117 |
| 60-69 | 1.0(0.6-1.8) |  |  | 1.2(0.6-2.5) |  |  | 1.0(0.6-1.9) |  |  | 0.9(0.3-2.2) |  |  | 1.7(0.9-3.5) |  |  | 2.7(1.0-6.9) |  |
| 70+ | Referent |  |  | Referent |  |  | Referent |  |  | Referent |  |  | Referent |  |  | Referent |  |
| Effect of other stressful life events on quality of life |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| No effect or event | Referent | 0.002 |  | Referent | 0.005 |  | Referent | 0.002 |  | Referent | 0.235 |  | Referent | 0.609 |  | Referent | 0.077 |
| A little/somewhat | 1.6(1.0-2.6) |  |  | 1.6(0.8-2.9) |  |  | 1.9(1.1-3.3) |  |  | 1.4(0.7-2.8) |  |  | 0.9(0.5-1.7) |  |  | 0.7(0.3-1.5) |  |
| Quite a bit/very much | 3.1(1.6-5.7) |  |  | 3.2(1.6-6.5) |  |  | 3.0(1.6-5.7) |  |  | 2.0(0.9-4.6) |  |  | 1.3(0.7-2.6) |  |  | 1.8(0.8-4.1) |  |
| Anxiety |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| Non-case | Referent | 0.028 |  | Referent | 0.078 |  | Referent | 0.046 |  | Referent | 0.073 |  | Referent | <0.001 |  | Referent | <0.001 |
| Sub-clinical/clinical | 1.8(1.1-3.1) |  |  | 1.7(0.9-3.2) |  |  | 1.7(1.0-2.9) |  |  | 1.9(0.9-3.8) |  |  | 4.0(2.3-7.2) |  |  | 4.2(2.0-8.7) |  |
| Depression: |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| Non-case | Referent | 0.393 |  | Referent | 0.007 |  | Referent | 0.744 |  | Referent | 0.328 |  | Referent | 0.261 |  | Referent | 0.448 |
| Sub-clinical/clinical | 1.3(0.7-2.6) |  |  | 2.6(1.3-5.2) |  |  | 0.9(0.5-1.7) |  |  | 1.5(0.7-3.3) |  |  | 1.5(0.7-2.9) |  |  | 1.4(0.6-3.1) |  |
| Accessed support service for melanoma |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| No | Referent | 0.028 |  | Referent | 0.182 |  | Referent | 0.275 |  | Referent | 0.915 |  | Referent | 0.001 |  | Referent | 0.010 |
| Yes | 1.7(1.1-2.6) |  |  | 1.5(0.8-2.5) |  |  | 1.3(0.8-2.1) |  |  | 1.0(0.5-2.0) |  |  | 2.5(1.5-4.2) |  |  | 2.4(1.2-4.8) |  |

a At least 1 moderate-to-high need at both baseline and on at least 1 follow-up survey.

b 10 and c 4 participants dropped out of this model due to having moderate-to-high needs at baseline and no follow-up data (i.e. persistent needs score could not be calculated).