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Patient Preferences for Follow-up After Recent Excision of a Localized Melanoma

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IMPORTANCE The standard model of follow-up posttreatment of localized melanoma relies on clinician detection of recurrent or new melanoma, through routinely scheduled clinics (clinician-led surveillance). An alternative model is to increase reliance on patient detection of melanoma, with fewer scheduled visits and increased support for patients' skin self-examination (SSE) (eg, using smartphone apps to instruct, prompt and record SSE, and facilitate teledermatology; patient-led surveillance).

OBJECTIVE To determine the proportion of adults treated for localized melanoma who prefer the standard scheduled visit frequency (as per Australian guideline recommendations) or fewer scheduled visits (adapted from the Melanoma Follow-up [MELFO] study of reduced follow-up).

DESIGN, SETTING, AND PARTICIPANTS This survey study used a telephone interview for surveillance following excision of localized melanoma at an Australian specialist center. We invited a random sample of 400 patients who had completed treatment for localized melanoma in 2014 to participate. They were asked about their preferences for scheduled follow-up, and experience of follow-up in the past 12 months. Those with a recurrent or new primary melanoma diagnosed by the time of interview (0.8-1.7 years since first diagnosis) were asked about how it was first detected and treated. SSE practices were also assessed.

MAIN OUTCOMES AND MEASURES Proportion preferring standard vs fewer scheduled clinic visits, median delay between detection and treatment of recurrent or new primary melanoma, and SSE practices.

RESULTS Of the 262 people who agreed to be interviewed, the mean (SD) age was 64.3 (14.3) years, and 93 (36%) were women. Among the 230 people who did not have a recurrent or new primary melanoma, 149 vs 81 preferred the standard vs fewer scheduled clinic visits option (70% vs 30% after adjusting for sampling frame). Factors independently associated with preferring fewer visits were a higher disease stage, melanoma on a limb, living with others, not having private health insurance, and seeing a specialist for another chronic condition. The median delay between first detection and treatment of recurrent or new primary melanoma was 7 and 3 weeks, respectively. Only 8% missed a scheduled visit, while 40% did not perform SSE or did so at greater than 3-month intervals.

CONCLUSIONS AND RELEVANCE Some patients with melanoma may prefer fewer scheduled visits, if they are supported to do SSE and there is rapid clinical review of anything causing concern (patient-led surveillance).

Supplemental content

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The incidence of melanoma is increasing in countries with predominantly European ancestry, with an estimated 351 880 new cases diagnosed worldwide in 2015.[1] Large increases in the numbers of new melanomas are projected for the next 2 decades.[2] Much of this is localized disease (American Joint Cancer Committee [AJCC] stages 0, I, or II), with increasing detection of in situ melanomas and thin invasive melanomas (Breslow thickness <1 mm) over time.[3-5] More people previously treated for localized melanoma are now in routinely scheduled follow-up, with a trend to increasing visit frequency for such patients.[6]

This current model of posttreatment follow-up relies on clinician detection of recurrent or new melanoma at a routinely scheduled visit (clinician-led surveillance). The potential benefits of routinely scheduled visits to facilitate early detection and treatment need to be balanced against possible harms and costs (both financial and opportunity). Some patients cite routine scheduled follow-up visits as one driver for their fear that the melanoma may recur or a new one develop.[7] Routinely scheduled follow-up also consumes clinician time and health resources and incurs out-of-pocket costs to the patient, with fewer resources available to be spent on other aspects of melanoma care.[8-11] The possibility for resource savings is demonstrated by the recent report from the Melanoma Follow-up (MELFO) trial, which found a 45% reduction in hospital costs at 1-year for the group randomized to reduced follow-up.[12]

Despite the current system of clinician-led surveillance with routinely scheduled clinic visits, about two-thirds of all recurrences and nearly half of all new primary melanomas are patient- or partner-detected in the intervals in-between visits.[13-15] Patient-led surveillance is an alternative model for lower-risk patients, where there is increased reliance on patient detection of melanoma, with fewer routinely scheduled visits and increased support for patients' skin self-examination (SSE) (achieved through a number of different approaches[16,17]) and timely access (<2 weeks) to specialist review if the patient detects anything that is a cause for concern.[18]

To explore patient preferences for scheduled clinic frequency and their actual experiences of follow-up, we undertook a telephone interview among people who had been treated for localized melanoma at the Melanoma Institute Australia (MIA), a large Australian melanoma treatment center, during the 2014 calendar year. The study had 3 objectives: (1) for patients without a recurrence or new primary melanoma, we sought to determine their stated preferences for standard vs fewer scheduled visits and their actual attendance at follow-up visits in the past 12 months; (2) for patients with a recurrence or new primary melanoma, we sought to assess the mechanisms for detection and treatment; and (3) for all patients, we evaluated SSE practices.

Key Points

Question Do patients with melanoma prefer the currently recommended schedule of follow-up or fewer visits, including not continuing follow-up after the first year for patients with stage 0/1A, and after the second year for those with stage 1B?

Findings In this survey study of 230 patients without recurrent or new primary melanoma, 149 preferred currently recommended and 81 preferred fewer scheduled visits. Higher stage, melanoma on a limb, living with others, no private health insurance, and another chronic condition were independently associated with a preference for fewer visits.

Meaning Some patients with early-stage melanoma who do not have a new or recurrent melanoma may prefer fewer scheduled visits.

Methods

Study Population and Setting

We conducted a telephone interview among a stratified random sample of participants diagnosed as having localized melanoma and treated at MIA. The study was approved by The University of Sydney human research ethics committee and by the MIA governance committee. They all provided written informed consent, and none were financially compensated. Details of how potential participants were selected are provided in a report on a self-administered questionnaire on fear of melanoma recurrence that was run in parallel to this study[19] (eAppendix 1 in the Supplement). Briefly, administrative data were used to define all 902 people diagnosed and treated for localized melanoma between January and December 2014 at MIA. At the time of sampling (July 24, 2015), 5 people had died, leaving 897 people. We randomly selected 351 people from 2 strata based on stage (177 from stage 0/I and 174 from stage II), and all of the 49 people known to have a recurrent or new primary melanoma (1 person with a new primary at time of the sampling did not have this recorded in the database). People treated for stage II melanoma and those who had a recurrence or new primary were oversampled to ensure that they were sufficiently represented in the study sample. We calculated that a sample size of 200 participants was required to obtain a 95% CI for the proportion of participants who preferred patient-led follow-up with a 95% CI no greater than ±7%, assuming that 50% would prefer patient-led surveillance (this is the most conservative assumption: if fewer or greater than this prefer patient-led surveillance then the required sample size is smaller). We estimated that 50% of individuals would agree to participate, and therefore invited 400 people to be in the study (by written invitation).

Telephone Interview

We engaged an independent research organization (Hunter Research Foundation) to conduct the telephone interviews. The interview questions were based on a survey questionnaire developed by the investigators, and included 19 questions about participants' preferences for follow-up schedule, experience of, and actual attendance at, follow-up in the past 12 months, as well as the mechanisms of detection and treatment of recurrent or new primary melanoma (eAppendix 2 in the Supplement). For the questions on preferred scheduled follow-up, we created standard vs fewer scheduled visit alternatives for each AJCC substage (**Table 1**). The standard visit frequency option was based on current Australian guideline recommendations,[20] and the fewer scheduled visits option was adapted from the

Table 1. Preference of Alternative Follow-up Strategies Presented to Participants

AJCC Substage	Fewer Visits	Standard Visits	Key Difference Between Fewer and Standard Visits
0	1 Visit with melanoma specialist in the first year then no further scheduled visits	1 Scheduled visit with melanoma specialist per year	Retain annual scheduled visit with specialist in first year but none thereafter
IA	1 Visit with melanoma specialist in the first year then no further scheduled visits	2 Scheduled visits with melanoma specialist per year	Decreased to annual scheduled visit with specialist in first year and none there after
IB	2 Visits with melanoma specialist in the first year then 1 visit in the second year and then no further scheduled visits	2 Scheduled visits with melanoma specialist per year	Decreased to annual scheduled visit with specialist in second year and none thereafter
IIA	2 Visits with melanoma specialist per year in first and second years, then 1 scheduled visit per year	3 Scheduled visits with melanoma specialist per year	Decreased to 2 scheduled visits with specialist in first and second years and annual visit in third year and thereafter
IIB/C	3 Visits with melanoma specialist in the first year, 2 visits in the second year, then 1 scheduled visit per year.	3-4 Scheduled visits with melanoma specialist per year	Retain 3 scheduled visits with specialist in first year, decreasing to 2 visits in second year, and to annual visit in third year and thereafter

Abbreviation: AJCC, American Joint Committee on Cancer.

[a] Participants were asked to choose between 2 potential alternative follow-up strategies with standard or decreased frequency of scheduled visit with a melanoma physician according to Australasian guideline recommendations.[20] The 2 options presented to the participant differed depending on the AJCC stage for the index melanoma the participant had been treated for. For the patient-led surveillance/fewer visits option, participants were told that this would be complemented by increased education and support of their self-examination, and that they would be able to visit a specialist at short notice if they had any concerns.

[b] Each participant was only offered the alternatives corresponding to their own AJCC substage.

intervention arm of the MELFO study of reduced follow-up. By the time of the interviews (held between August 31 and November 31, 2015), 32 participants had developed a recurrent or new primary melanoma (these were diagnosed 0.8 to 1.7 years from time of their first primary diagnosis). Responses about recurrent or new primary melanoma were verified against the MIA database (after a lag time of over 12 months to allow for delays in data entry). Interviewers used computer-assisted telephone interview to refine the questions.

Statistical Analysis

We first calculated summary statistics (means [SDs] or medians [interquartile ranges] for continuous data, and frequencies [percentages] for categorical data) for demographic and clinical variables for: the full population (all people treated for localized melanoma at MIA during 2014), potential participants, and actual participants. The following variables were examined: age at diagnosis, AJCC stage at initial presentation, anatomic site of primary lesion, diagnosis of recurrence or new primary melanoma, age at study entry, and sex. We then compared characteristics for participants who stated they would prefer fewer scheduled visits and those who would not, and explored potential associations using univariable and multivariable logistic regression. For the multivariable models, we initially included all covariates with $P < .25$ in univariable analyses, and used stepwise backward selection to identify characteristics independently associated with a preference for fewer scheduled visits.

We calculated summary statistics for variables relating to the detection and treatment for people with recurrence or new primary melanoma, and SSE practices stratified by presence of recurrent or new primary melanoma at the time of phone interview.

We adjusted all estimated means and proportions for our sampling frame by reweighting the estimates to account for oversampling of participants with an index melanoma that was stage II and who had recurrent or new primary melanoma. Stata/IC statistical software (version 11.2; StataCorp) was used for analysis.

Results

Of the 400 potential participants we approached for the telephone interview, 262 (66%) agreed to participate (eAppendix 1 in the Supplement). Their mean (SD) age was 64.3 (14.3) years, and 93 (36%) were women. Clinical and demographic characteristics of actual and potential participants were similar and are presented in **Table 2**. The stratified random sampling ensured that there were more participants with stage II disease and recurrent or new primary melanoma compared with the full population.

Preferences for Scheduled Follow-up Frequency

Table 3 presents stated preferences for fewer vs standard scheduled follow-up frequency by AJCC substage in the 230 respondents who had not had recurrent or new primary melanoma diagnosed. The proportion of participants within each substage, who said that they would prefer the fewer scheduled visits option, ranged from 17% (6 of 36 patients with stage 0) to 48% (23 of 48 patients with stage IIB/C). The overall proportion who preferred fewer visits was 30% (95% CI, 25%-36%; adjusted for the oversampling of stage II patients in our study design). There was very strong evidence that proportionately fewer participants with stage 0/I (33 of 127 [26%]) than stage II (48 of 103 [47%]) melanoma preferred fewer scheduled visits, after adjusting for other significant associations ($P < .001$). More participants seeing a specialist for another chronic health problem or comorbidity ($P = .03$), who did not have private health insurance ($P = .006$), who lived with others ($P = .001$), and who had their first primary melanoma on a limb ($P = .01$) preferred fewer scheduled visits. There were no other independently significant associations, including the participant level of fear of recurrent or new primary melanoma, as measured by the Fear of Cancer Recurrence Inventory[24] ($P = .23$).

Missed Follow-up

Questions about experiences of follow-up in the past year revealed that only 13 participants (5%; 95% CI, 3%-8%)

Table 2. Characteristics of People Treated for Localized Melanoma[a]

Sociodemographic and Clinical Characteristics	No. (%)		
	All People Treated at MIA in 2014 (n = 897)[b]	Potential Participants (n = 400)	Phone Interview Participants (n = 262)[c]
Age, mean (SD), y	62.7 (15.6)	65.0 (15.6)	64.3 (14.3)
Sex			
Male	523 (58)	250 (63)	169 (65)
Female	374 (42)	150 (38)	93 (36)
Highest educational attainment			
Did not complete secondary school	NA	NA	65 (25)
Completed secondary school			63 (24)
Completed certificate or trade			73 (28)
Completed university degree			60 (23)
Married/de facto	NA	NA	192 (74)
Living with others	NA	NA	207 (79)
Have private insurance	NA	NA	188 (72)
Outdoor occupation	NA	NA	27 (10)
SEIFA category[d]			
Low socioeconomic status (deciles 1-3)	NA	67 (17)	49 (19)
Medium to high socioeconomic status (deciles 4-10)		333 (83)	213 (81)
Remoteness area[e]			
Major cities in Australia	NA	300 (75)	193 (74)
Inner regional Australia		84 (21)	55 (21)
Outer regional Australia		16 (4)	14 (5)
AJCC stage			
Stage 0	185 (21)	60 (15)	41 (16)
Stage IA	195 (22)	56 (14)	42 (16)
Stage IB	299 (33)	86 (22)	61 (23)
Stage IIA	108 (12)	95 (24)	63 (24)
Stage IIB/C	110 (12)	103 (26)	55 (21)
Anatomic site of primary lesion			
Limb	410 (46)	178 (45)	122 (47)
Trunk	298 (33)	131 (33)	84 (32)
Head/neck	189 (21)	91 (23)	56 (21)
Had a recurrent or new primary melanoma at time of interview (0.8 to 1.7 y since first diagnosis)	50 (6)	49 (12)	32 (12)
Age at diagnosis, mean (SD), y	60.8 (15.5)	63.1 (15.6)	62.4 (14.3)
Has other chronic health problem/ comorbidity under specialist care	NA	NA	66 (25)

Abbreviations: AJCC, American Joint Committee on Cancer; MIA, Melanoma Institute Australia; NA, not available; SEIFA, Socio-Economic Indexes for Areas.

[a] All values reported are frequencies (column percentages) unless otherwise indicated. Percentages may not sum to 100 owing to rounding.

[b] Excluded people who had died prior to sampling for the study (n = 5).

[c] Missing data for education level (n = 1) and marital status (n = 2).

[d] Based on Postal Area Index of Relative Socio-Economic Advantage and Disadvantage, Australian Bureau of Statistics 2011.[21]

[e] Based on 1270.0.55.006C190 Postcode 2012 to Remoteness Area 2011, Australian Bureau of Statistics 2011.[22]

reported missing some of their routine follow-up appointments, while an additional 8 (4%) reported to have no follow-up visits (95% CI, 2%-7%; adjusted for the oversampling of stage II patients in our study design). Reasons for missed appointments reflected uncertainties about follow-up schedules (eAppendix 3 and eAppendix 4 in the Supplement).

Detection and Treatment of Recurrent or New Primary Melanoma

Of the 262 participants, at the time of their interview (0.8-1.7 years since time of first primary melanoma) 13 (5%) had a recurrence (includes local, in-transit, regional, or distant recurrence), and 19 (7%) had a new primary melanoma (**Table 4**). In the full cohort of people treated for localized melanoma, 50 of 902 (6%) had a recurrent or new primary melanoma. Of the people with a recorded history of recurrent or new primary melanoma according to the MIA database by the time of phone interview, 6 of 13 (46%) and 16 of 19 (84%) stated that they were not aware that they had a recurrence or new primary melanoma, respectively. Half of those who stated that they were aware of their recurrent or new primary melanoma (5 of 10) reported that this was first noticed (detected) by someone other than their specialist physician (by self for 3 people with recurrence and 1 with new primary and by their primary physician in 1 person with recurrence). Although estimates were based on few people, the time from when the lesion was first noticed to when it was treated was longer for recurrence (includes local, in transit, nodal, or distant recurrence; median, 7 weeks), than for new primary melanoma (median, 3 weeks),

Table 3. Follow-up Preferences for Participants Without Recurrent or New Primary Melanoma[a,b]

Characteristic	Preferred Fewer Visits (n = 81)	Did Not Prefer Fewer Visits (n = 149)	COR (95% CI)	*P* Value	AOR (95% CI)[c]	*P* Value
Age, mean (SD), y	62.8 (13.8)	62.6 (12.9)	1.00 (0.98-1.02)	.90	1.00 (0.98-1.02)	.75
Sex				.08		.10
Female	31 (36)	52 (64)	1 [Reference]		1 [Reference]	
Male	50 (26)	97 (74)	0.63 (0.37-1.06)		0.63 (0.36-1.09)	
Highest educational attainment[d]				.16		.13
Did not complete secondary school	26 (39)	32 (61)	1 [Reference]		1 [Reference]	
Completed secondary school	20 (29)	34 (71)	0.64 (0.32-1.30)		0.61 (0.29-1.27)	
Completed certificate or trade	17 (22)	46 (78)	0.44 (0.22-0.89)		0.39 (0.18-0.85)	
Completed university degree	18 (30)	36 (70)	0.65 (0.32-1.33)		0.61 (0.26-1.41)	
Marital status[d]				.43		.98
Single/never married	5 (23)	15 (77)	1 [Reference]		1 [Reference]	
Married/de facto	63 (33)	106 (67)	1.66 (0.62-4.42)		1.11 (0.25-4.84)	
Divorced	4 (24)	11 (76)	1.07 (0.26-4.46)		0.87 (0.22-3.39)	
Widowed	9 (23)	15 (77)	1.00 (0.31-3.21)		1.03 (0.26-3.99)	
Living arrangements				.002		.001
Alone	10 (15)	39 (85)	1 [Reference]		1 [Reference]	
With others	71 (34)	110 (66)	3.08 (1.52-6.23)		3.80 (1.67-8.63)	
Have private insurance				.05		.006
Yes	54 (27)	114 (73)	1 [Reference]		1 [Reference]	
No	27 (39)	35 (61)	1.74 (1.00-3.05)		2.42 (1.29-4.56)	
Occupation				.12		.21
Indoor	75 (31)	133 (69)	1 [Reference]		1 [Reference]	
Outdoor	6 (18)	16 (82)	0.50 (0.21-1.19)		0.55 (0.22-1.40)	
SEIFA category[e]				.21		.59
Low (deciles 1-3)	16 (38)	25 (63)	1 [Reference]		1 [Reference]	
Medium to high (deciles 4-10)	65 (28)	124 (72)	0.66 (0.34-1.27)		0.83 (0.43-1.62)	
Remoteness area[f]				.53		.85
Major cities in Australia	56 (29)	114 (71)	1 [Reference]		1 [Reference]	
Inner regional Australia	20 (36)	26 (64)	1.35 (0.73-2.52)		1.14 (0.57-2.26)	
Outer regional Australia	5 (24)	9 (76)	0.78 (0.28-2.19)		0.82 (0.30-2.21)	
AJCC stage				<.001		<.001
Stage 0/I	33 (26)	94 (74)	1 [Reference]		1 [Reference]	
Stage II	48 (47)	55 (53)	2.46 (1.73-3.57)		2.54 (1.74-3.71)	
Anatomic site of primary lesion				.06		.01
Limb	42 (35)	62 (65)	1 [Reference]		1 [Reference]	
Trunk	27 (31)	50 (70)	0.81 (0.46-1.44)		0.88 (0.47-1.65)	
Head/neck	12 (19)	37 (81)	0.42 (0.21-0.86)		0.36 (0.18-0.72)	
Age at diagnosis, mean (SD), y	60.8 (14.0)	60.7 (12.9)	1.00 (0.98-1.02)	.91	1.00 (0.98-1.02)	.74
FCRI severity subscale score, mean (SD)[d]	13.5 (8.5)	14.9 (6.3)	0.97 (0.92-1.03)	.31	0.96 (0.91-1.02)	.23
Other chronic health problem/ comorbidity under specialist care				.05		.03
No	59 (27)	118 (73)	1 [Reference]		1 [Reference]	
Yes	22 (40)	31 (60)	1.82 (1.01-3.28)		2.05 (1.06-3.94)	

Abbreviations: AJCC, American Joint Committee on Cancer; AOR, adjusted odds ratio; COR, crude odds ratio; FCRI, Fear of Cancer Recurrence Inventory; SEIFA, Socio-Economic Indexes for Areas.

[a] All values reported are frequencies (row percentages) unless otherwise indicated. Percentages may not sum to 100 owing to rounding. Percentages are adjusted for stratified sampling of people without recurrent or new primary melanoma.

[b] Data are not available on race/ethnicity for the study population. A recent Australian population-based study estimated 99% of melanomas occurred in people of white ethnicity.[23]

[c] Adjusted for other independently significant predictors: AJCC stage, anatomic site of primary lesion, other chronic health problem/comorbidity under specialist care, living arrangements, and having private insurance.

[d] Missing data for FCRI severity subscale score (n = 90), education level (n = 1), and marital status (n = 2).

[e] Socio-Economic Indexes for Areas (SEIFA) is based on Postal Area Index of Relative Socio-Economic Advantage and Disadvantage, Australian Bureau of Statistics 2011.[21]

[f] Based on Australian Statistical Geography Standard Catalogue Number 1270.0.55.006 Postcode 2012 to Remoteness Area 2011, Australian Bureau of Statistics 2011.[22]

Table 4. Detection and Treatment of Recurrent or New Primary Melanoma[a]

Characteristic	No. (%)	
	Recurrent Melanoma (n = 7)[b]	New Primary Melanoma (n = 3)[c]
Detection mechanism		
Self	3 (43)	1 (33)
Partner	0	0
Relative or friend	0	0
GP	1 (14)	0
Specialist	3 (43)	2 (67)
Saw multiple physicians before final diagnosis of the recurrent or new primary melanoma	7 (100)	1 (33)
Time to treatment, median (IQR), wk	7 (14)	3 (6)
Treating physician		
Primary physician	0	0
Specialist physician	7 (100)	3 (100)
Don't know	0	0
Treatment of melanoma		
Surgery	6 (86)	3 (100)
Other/not sure	2 (29)	0

Abbreviations: GP, general practitioner; IQR, interquartile range.

[a] All values reported are frequencies (column percentages) unless otherwise indicated.

[b] Data do not include people who were unaware that they had recurrent melanoma when interviewed (n = 6). Of the 7 people with recurrence included in this table, 1 had a distant metastasis, 3 had regional lymph nodes, 2 had in-transit recurrence, and 1 had local recurrence.

[c] Data do not include people who were unaware that they had new melanoma when interviewed (n = 16).

Table 5. Skin Self-examination (SSE) Practices in the Past Year for People Treated for Localized Melanoma[a]

SSE Practices	% (95% CI)	
	Without Recurrence or New Primary (n = 230)[b]	With Recurrence or New Primary (n = 32)
Frequency of SSE		
Weekly	8 (6-12)	16 (5-33)
Fortnightly	7 (5-11)	3 (0.1-16)
Monthly	23 (18-28)	9 (2-25)
Every 2 mo	10 (7-14)	6 (1-21)
Every 3 mo	9 (6-13)	9 (2-25)
Longer than 3-mo intervals	14 (10-19)	9 (2-25)
Did not perform SSE	30 (25-35)	47 (29-65)
Who performed SEE		
Self	24 (19-30)	9 (2-25)
Family member	4 (2-8)	6 (1-21)
Self and family member	42 (36-48)	38 (21-56)
Did not perform SSE	30 (25-35)	47 (29-65)
Examines all body parts, including hard-to-see areas[c]	44 (38-50)	31 (16-50)
Examines skin with a full-length mirror[d]	53 (47-59)	42 (25-61)
Confidence to detect recurrent or new primary melanoma		
Very confident	9 (6-13)	6 (1-21)
Confident	30 (24-35)	34 (19-53)
Not entirely confident	25 (20-31)	13 (4-29)
Not at all confident	7 (5-11)	0
Did not perform SSE	30 (24-35)	47 (29-65)

[a] Percentages are of column totals.

[b] Adjusted for our oversampling of stage II patients to be potential participants. This adjustment means that our estimates more accurately represent the skin self-examination practices for the full cohort of patients (rather than being unduly influenced by stage II patients).

[c] Missing data for a participant without recurrence or new primary melanoma (n = 1).

[d] Missing data for a participant with recurrence or new primary melanoma (n = 1).

corresponding to a higher number of visits to different physicians before a final diagnosis was made. A large number of recurrent or new primary melanomas were surgically treated, and all were treated by specialists (at MIA or outside MIA).

SSE Practices

Table 5 summarizes participants' responses about SSE. Among participants without recurrent or new primary melanoma, 30% (95% CI, 25%-35%) did not perform regular SSE, and a further 14% (95% CI, 10%-19%) did so less frequently than every 3 months (percentages adjusted for stratified sampling). Only 42% (95% CI, 36%-48%) did their SSE jointly with a family member, 44% (95% CI, 38%-50%) examined all parts of the body, 53% (95% CI, 47%-59%) used a full-length mirror, and 38% (95% CI, 33%-44%) were confident or very confident in their ability to perform SSE. Comparatively fewer participants with a recurrent or new primary melanoma performed regular SSE (47%; 95% CI, 29%-65%) did not perform SSE at all], and were less thorough and confident about their ability to do so.

Discussion

Just less than one-third of the people treated for localized melanoma without a recurrence or new primary melanoma since their initial diagnosis (0.8-1.7 years prior), indicated they would prefer fewer scheduled visits as long as there was increased support for SSE and timely access (<2 weeks) to specialist review if they detected anything that was a cause for concern. A preference for fewer scheduled visits may reflect the financial and opportunity costs of scheduled visits[25] (seeing a specialist for another chronic health problem or comorbidity, and not having private health insurance), or when a greater reliance on patient-led surveillance is more practical (living with others, and having a primary melanoma on a limb). More generally, people might prefer routinely scheduled visits because they like face-to-face encounters, are not confident in using/do not trust resources to support SSE, or are not confident in their ability to do SSE. Others might prefer fewer visits not only because of financial costs, but also because of work commitments, travel needed to get to clinic appointments, a lack of trust in the hospital/medical system, limited time because of other physician visits, because they are experiencing depression, or are less motivated to attend for health care. Only a minority of respondents reported missing scheduled follow-up (8 of 262 [3%] not attending any follow-up), suggesting our sample may be more adherent with follow-up than people treated for localized melanoma in general.[9] The responses indicated a variety of reasons

for why they missed follow-up, and this may be explored further in other less adherent populations.

Only 7 of 13 and 3 of 16 of respondents recorded to have a recurrence or new primary diagnosis, respectively, in the MIA database reported this to the interviewer. This may be partly explained by the fact that 8 of these people had in situ melanoma as either first primary or second primary diagnosis (so they may not have thought both were melanomas as such), and a further 5 had the 2 primary melanomas diagnosed close together in time (<1 month apart, so they may not have appreciated that these were different episodes). Nonetheless, our results do highlight the importance of clear communication with the patient and family to ensure important information such as this is being understood. The time from when the abnormality was first noticed/detected and finally treated, although not excessively long, might still be streamlined further. There also seems to be considerable room for improvement in SSE practice. Around 40% of respondents either did not perform SSE at all, or did so less frequently than at 3-month intervals, and less than half of the participants asked a family member to help, or examined parts of the body that were difficult to see. Patients with a recurrence or new primary melanoma seemed less likely to perform SSE, despite being at higher risk for a further event.

Strengths and Limitations

An important strength of this study is that we used an epidemiological design for selecting potential participants from all individuals undergoing treatment for localized melanoma at a large specialist center over a defined period of time (ie, an inception cohort). We used stratified random sampling, oversampling for stage II patients or those with recurrent or new primary melanoma to ensure these subgroups were adequately represented. We adjusted estimated means and proportions for the disproportionate stratified random sampling design so that our results would be representative of the full cohort. Responses about recurrent or new primary melanoma were verified with a high-quality database to ensure reliability, with further interrogation of the database at more than 12 months after the interviews to allow for possible delay in data entry.

There are several limitations in our study. Selection bias, because of participants who are more adherent to follow-up and SSE than the full inception cohort, may mean we underestimated the proportion of people who would prefer fewer scheduled visits, who miss follow-up, and who do not do SSE. In addition, recall bias may have also caused us to underestimate the time between detection and treatment of recurrent or new primary melanoma. There were some inconsistencies in stated preference for scheduled visit frequency elicited from the choice of alternative options compared with comments made by the participants. Although we did not classify these participants as preferring fewer scheduled visits if their comments suggested elsewise, this indicates that some participants misunderstood the direct question on the alternate follow-up frequencies.

Although our results indicate that most people did not prefer fewer scheduled visits, this may be due in part to the size of the reduction in scheduled visits we presented. For example, the fewer scheduled visits option for stage 0 (preferred by only 17%) included only 1 visit with a melanoma specialist in the first year and then no further scheduled visits, compared with continued annual visits for standard scheduled visits option. In contrast, fewer scheduled visits for stage IIB/C (preferred by 48%) included a more gradual reduction down to annual visits by the third year postdiagnosis. Thus, the exact proportion preferring the fewer scheduled visits option is likely to be very context specific, and this may make generalization difficult. For example, in the Netherlands (where the MELFO study was conducted), patients with stage 0 or IA melanomas are routinely discharged from specialist follow-up after the postsurgical visit and so the fewer scheduled visit option for such patients in our study is already the standard of care in that country,[26] and is accepted by patients and clinicians. The exact differences between a system of patient-led vs clinician-led surveillance will also be context specific. This will in part be determined by the specific frequency of routinely scheduled visits and resources used to support SSE in the current clinician-led surveillance, as well as the degree to which these are changed in the new patient-led surveillance model.

We did not provide patients with detailed information regarding the rationale for follow-up in the less frequent visit option (eg, more frequent follow-up in the first 2 years following thicker melanoma because the recurrence rate is much higher during this time). If more information was provided prior to questioning the patients on their preferences of follow-up, responses may have differed. An analysis of administrative data from MIA suggested that most people may be attending follow-up less frequently than guidelines recommend, at least at the specialist center.[9] Explanations for the discrepancy between those findings and the results of the current study include variations between clinicians as to how frequently they recommend follow-up,[27] follow-up occurring outside of the specialist center, and nonrepresentativeness of our study group in terms of adherence to the follow-up offered.

Conclusions

Patients seem to accept the visit frequency recommended by clinicians,[7] and clinicians may recommend fewer visits provided they are reassured of the safety of doing this—with participant ability in SSE a key determinant.[28] Using online videos and smartphone apps to instruct, prompt, and record SSE, and to facilitate teledermatology may increase patient detection of recurrent and new melanoma and allow scheduled visit frequency to be reduced. The feasibility of such an intervention is being tested in an Australian randomized clinical trial.[17]

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