

INVESTIGATIVE REPORT

Total Body Photography as an Aid to Skin Self-examination: A Patient's Perspective

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Skin self-examination can help patients who are at high risk for developing melanoma to become more involved in their own surveillance and treatment. This study examined the use of total body photography as an aid to skin self-examination from the patients' perspective. A total of 179 individuals at high risk for developing melanoma who had undergone total body photography (60.5% response rate) completed a self-reported questionnaire assessing the frequency of skin self-examination, perceived usefulness of total body photography, and a variety of potential demographic, clinical and psychological factors. Only approximately half of the participants indicated skin self-examination as useful and 78.9% preferred clinical skin examination by a specialist. Finding total body photography useful was associated with having received instructions on how to perform skin self-examination, the use of a (hand)mirror, and confidence to detect changing moles. These findings allow us to develop strategies to further improve patients' self-screening behaviours. Key words: melanoma; pigmented lesions; skin self-examination; total body photography; prevention.

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Incidence rates of melanoma have been increasing rapidly worldwide for decades. In the Netherlands, the age-standardized incidence (European Standardized Rate per 100,000 person-years) of melanoma has increased from 11.3 to 26.2 between 1989 and 2012 (1, 2) and is expected to increase even further (3).

Strategies to increase early detection of melanoma include regular clinical skin examination (CSE) as well as skin self-examination (SSE). Through easy access to the internet, today's patients are well-informed and patients' self-reliance continues to grow. Therefore, patients are becoming more involved in their health management. The Dutch Melanoma Guideline (4) recommends performing routine CSE (once or twice every year) as well as SSE (every 2 months) on individuals at high risk of developing melanoma.

Baseline total body photography (TBP) provides a means to compare lesions during follow-up, allowing doctors and patients to recognize new and changing lesions at an early stage. Previous studies have shown that photographically assisted follow-up helps in detecting new and slightly changing moles, which do not display the clinical features of melanoma (5–10). It may also be an effective way to increase sensitivity and specificity for detecting melanoma, as it is valuable in avoiding unnecessary biopsy in suspicious, but stable, lesions. In addition, TBP has proven useful in detecting non-melanoma skin cancer (5).

At our pigmented lesions clinic, patients at high risk of developing melanoma are given a compact disk (CD) storing their total body photographs. Several studies have proven the added value of TBP in the detection of melanoma (5–10). However, all studies were aimed at the clinical relevance of TBP. To our knowledge, there has been no previous study focussing on the patient's, rather than the doctor's, point of view. In order to help improve patients' SSE behaviour it is important to identify factors associated with the uptake of screening behaviours. Therefore, the aims of this study were 3-fold: (i) to examine the use of TBP and the uptake of related SSE among patients at high risk of developing melanoma; (ii) to determine patient experiences with TBP as an aid to SSE; and (iii) to identify the demographic, clinical and psychosocial factors associated with the uptake of screening behaviours, all in order to improve patients' SSE.

METHODS

Participants

A total of 318 patients who had undergone TBP at the Leiden University Medical Center between 2005 and 2011 were identified in the Clinical Assistant database (available for storage of images in hospitals). Seven of these 318 patients had deceased before the start of this study, leaving 311 eligible participants. All 311 eligible patients were at high risk for developing melanoma, either because of family history (familial atypical multiple mole melanoma (FAMMM) syndrome) or the presence of numerous (>5) atypical naevi. They all received CSEs once or twice every year. Patients were told to perform SSE every 2 months. Patients with FAMMM syndrome who have a mutation in the *CDKN2A* gene have a relative risk (RR)>100 of developing melanoma. Patients with numerous atypical naevi have a RR of 6.36 of developing melanoma. In the Netherlands, the European

standardized incidence rate of melanoma is 27.77 per 100,000 persons (11). Total body photographs consisted of a standardized series of poses, as described previously by Halpern et al. (12).

Clinical characteristics were obtained from patient records containing data on: family history, dysplastic naevus syndrome, the amount of atypical naevi, personal history of melanoma and number of excisions of suspected lesions performed at the Leiden University Medical Center.

Procedure

All eligible individuals received an invitation letter, along with the questionnaire and a pre-stamped envelope. Reminders were sent to individuals who had not completed the questionnaire within a specified time. Informed consent was obtained.

Questionnaire

The study questionnaire (Appendix S1¹) revealed data on demographic variables, the frequency of SSE, patients' perceived risk of developing melanoma, melanoma-specific distress, and the use of total body photography. Patients had been asked to indicate their agreement on several statements related to the performance of SSE and the use of TBP on a 5- or 7-point Likert scale.

Data analysis

Data were analysed using SPSS 17.0 (IBM company, Benelux). Statistical analysis was performed on 3 different behavioural outcomes: frequency of SSE; perceived usefulness of the CD with total body photographs; and patient's indication of using the CD with total body photographs when suspecting a new or changing mole. Associations with non-psychological variables were assessed using Pearson's χ^2 tests. All Likert scale scores were treated as ordinal data. Spearman's rank correlation coefficients (r_s) were used to examine associations between psychological variables and the 3 different categories of behavioural outcome variables. All p -values <0.05 were considered statistically significant.

RESULTS

A total of 311 eligible individuals were approached for participation. Of these, 194 individuals returned the questionnaire data; a response rate of 62.4%. However, 15 of these individuals indicated that they had never received the TBP, leaving 179 eligible participants. The mean \pm standard deviation (SD) age of the study population was 41 ± 11.0 years (60.3% female, 39.7% male). The majority of the study population (78.2%) had a partner and 24.9% of participants had a university degree. One-third (38.3%) of participants had a personal history of melanoma and 38.9% had at least 1 family member with a previous melanoma. Of participants, 75.3% had more than 5 atypical naevi at the time of TBP, 35.6% had been diagnosed with FAMMM syndrome.

Skin self-examination

Of the participants, 53.4% agreed that regular SSE helped to detect melanoma at an early stage, and 94.3%

believed that early discovery of melanoma results in a better survival. When performing SSE, 47.4% of the participants indicated that they were assisted by another person, only 17.5% used a (hand)mirror. Of the participants, 31.4% were confident that they were capable of detecting new moles and 37.2% were confident that they were able to detect changes in their moles. However, 40.4% and 44%, respectively, lacked the confidence and capability to detect new and changing moles. Of the participants, 54.5% knew what to look for when performing SSE, but only 10.9% were sure of being able to recognize skin cancer. Performing SSE was experienced as difficult by 57% of the participants, and 69.4% found it even nearly impossible because of their large number of moles. Of the participants, 78.9% preferred regular CSE over regular SSE and 22.2% indicated that they did not perform regular SSE because of regular CSE.

Frequency of SSE

Overall, 77.1% of participants reported performing SSE at least once in the past year, 14.5% performed SSE on a monthly basis and 4.5% indicated performing SSE weekly. Clinical and psychological variables associated with the frequency of SSE in the past year are shown in Table I. Participants with a partner performed SSE more frequently ($p < 0.05$), as did those who had undergone one or more excisions compared with those who had never had a mole excised ($p < 0.05$). A personal history of melanoma seemed to be an important predictor of SSE performance ($p < 0.001$). It also seems that patients who had discovered their previous melanoma themselves perform SSE more frequently compared with patients whose previous melanoma had been discovered by a doctor ($p < 0.005$).

Participants with more than 5 atypical naevi performed less frequent SSE compared with those with less than 5 atypical naevi ($p < 0.001$). No significant association was found between having received instruction on SSE and the reported frequency of SSE ($p = 0.227$).

The strongest psychological predictors of SSE were "not performing SSE, because of regular CSE" ($r_s = 0.545$, $p < 0.001$) and perceived risk of getting melanoma sometime in the future ($r_s = 0.303$, $p < 0.001$). Significant associations were also found for the use of a (hand)mirror when performing SSE ($r_s = 0.211$, $p < 0.005$), confidence in being able to detect new and changing moles ($r_s = 0.238$, $p < 0.001$ and $r_s = 0.216$, $p < 0.005$, respectively), the amount of time spent thinking about melanoma ($r_s = 0.289$, $p < 0.001$) and the influence of thoughts and feelings about melanoma on work and daily activities ($r_s = 0.272$, $p < 0.001$). Significant associations were found between the frequency of SSE and the doctor deciding to excise a mole ($r_s = 0.168$, $p < 0.05$) and the doctor deciding not to excise a mole ($r_s = 0.181$, $p < 0.05$) after comparison with TBP.

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Table I. Bivariate analysis of clinical and psychological variables associated with frequency of skin self-examination (SSE) in the past year

Variable	Test statistics		
	Mean (SD)	χ^2	<i>p</i> -value
Clinical variables			
Personal history of melanoma			
Previous melanoma	1.35 (0.73)	16.897	<0.001
No previous melanoma	0.89 (0.74)		
Previous melanoma discovered by			
Doctor	1.14 (0.73)	6.657	<0.05
Patient	1.69 (0.53)		
Number of FDRs and SDRs affected by melanoma			
0	1.07 (0.74)	3.911	0.418
1	1.00 (0.81)		
≥ 2	1.22 (0.73)		
Number of excisions			
0	1.00 (0.77)	9.082	0.059
1–3	1.06 (0.70)		
>3	1.09 (0.84)		
>5 atypical naevi			
Yes	0.96 (0.78)	13.312	<0.001
No	1.39 (0.61)		
Familial atypical multiple mole melanoma syndrome			
Yes	1.22 (0.74)	3.878	0.144
No	0.99 (0.77)		
Doctor or nurse instruction on SSE			
Yes	1.14 (0.74)	2.968	0.227
No	0.98 (0.81)		
		r_s	<i>p</i> -value
Psychological variables			
Help from another person when performing SSE		0.128	0.079
Use of a (hand)mirror when performing SSE		0.226	<0.005
Confidence in detecting changes in moles		0.230	<0.001
Confidence in detecting new moles		0.348	<0.001
Not performing SSE, because of regular CSE		0.545	<0.001
Perceived risk of getting melanoma in the future		0.145	0.051
Amount of time spent thinking about melanoma		0.210	<0.005
Influence of thoughts and feelings about melanoma on work and daily activities		0.283	<0.001
Photographs used by doctor on CSE		0.153	<0.05
Photographs made doctor decide to excise mole		0.191	<0.05
Photographs made doctor decide not to excise mole		0.198	<0.05

To interpret mean SSE scores, response options were: 1 = “not once”, 2 = “once to 3 times per year” and 3 = “more than 3 times per year”. Significant values are shown in bold.

SD: standard deviation; FDRs: first-degree relatives; SDRs: second-degree relatives; CSE: clinical skin examination.

Perceived usefulness of total body photography

Of the participants, 31.1% found TBP useful. However, 44.7% neither agreed nor disagreed, 14.8% found the photographs unclear and 27.9% indicated that they were ashamed of the photographs and did not want anyone else to see them. Of the participants, 68% indicated that the doctor had used the photographs on follow-up CSE. In 34.8% of these cases this led to the excision of a mole and in 35.7% of these cases this led to the doctor’s decision not to excise the mole because it did not show any signs of change.

Table II shows clinical and psychological variables associated with perceiving TBP as useful. Participants

Table II. Bivariate analysis of clinical and psychological variables associated with finding total body photography (TBP) useful

Variable	Test statistics			
	Not useful % (n)	Useful % (n)	χ^2	<i>p</i> -value
Clinical variables				
Personal history of melanoma				
Previous melanoma	39.5 (17)	30.4 (17)	0.909	0.340
No previous melanoma	60.5 (26)	69.6 (39)		
Previous melanoma discovered by				
Doctor	52.9 (9)	47.1 (8)	0.118	0.732
Patient	47.1 (8)	52.9 (9)		
Number of FDRs and SDRs affected by melanoma				
0	32.6 (14)	33.9 (19)	0.671	0.715
1	39.5 (17)	32.1 (18)		
≥ 2	27.9 (12)	33.9 (19)		
Number of excisions				
0	4.8 (2)	8.9 (5)	0.660	0.719
1–3	52.4 (22)	51.8 (29)		
>3	42.9 (18)	39.9 (22)		
>5 atypical naevi				
Yes	74.4 (32)	69.6 (39)	0.274	0.601
No	25.6 (11)	30.4 (17)		
Familial atypical multiple mole melanoma syndrome				
Yes	34.9 (15)	44.6 (25)	0.962	0.327
No	65.1 (28)	55.4 (31)		
Doctor or nurse instruction on SSE				
Yes	50.0 (20)	80.4 (41)	9.370	<0.05
No	50.0 (20)	19.6 (10)		
Frequency of SSE in the past year				
Not once	30.2 (13)	17.9 (10)	2.098	0.350
1–3 times/year	37.2 (16)	42.9 (24)		
>3 times/year	32.6 (14)	39.3 (22)		
		r_s	<i>p</i> -value	
Psychological variables				
Help from another person when performing SSE		0.064	0.532	
Use of a (hand)mirror when performing SSE		0.227	<0.05	
Confidence in detecting changes in moles		0.334	<0.001	
Confidence in detecting new moles		0.127	0.209	
Not performing SSE, because of regular CSE		0.108	0.286	
Perceived risk of getting melanoma in the future		0.003	0.974	
Amount of time spent thinking about melanoma		0.169	0.098	
Influence of thoughts and feelings about melanoma on work and daily activities		0.025	0.812	
Photographs used by doctor on CSE		0.155	0.154	
Photographs made doctor decide to excise mole		0.214	<0.05	
Photographs made doctor decide not to excise mole		0.306	<0.05	

To interpret mean SSE scores, response options were: 1 = “not once”, 2 = “once to 3 times per year” and 3 = “more than 3 times per year”. Significant values are shown in bold.

SSE: skin self-examination; FDRs: first-degree relatives; SDRs: second-degree relatives; CSE: clinical skin examination.

who had indicated neither agreeing nor disagreeing with the statement “I consider the CD with TBP to be useful” were not taken into account in the analysis. A significant association was found between having received SSE instructions from a nurse or doctor and finding TBP to be useful ($p < 0.005$). No association was found between considering TBP to be useful and the annual frequency of SSE ($p = 0.350$). Participants who indicated the use of a (hand)mirror during SSE or who indicated being confident in detecting changes in their moles were more likely to perceive TBP as useful

($p < 0.05$ and $p < 0.001$, respectively). Those participants whose doctor had previously decided to excise or not to excise a mole based on the total body photographs were more likely to find TBP to be useful ($p < 0.05$ and $p < 0.05$, respectively).

Using total body photography as an aid to skin self-examination

Only 6.2% of participants reported using TBP every time they performed SSE. Of the participants, 28% indicated that they only used TBP when they suspected a mole to be new or having changed, 47.5% reported no use of TBP during SSE, and 27.8% reported feeling more confident about being able to detect new or changing moles since they had received the CD with total body photographs, but only 14.2% of all participants had ever been reassured about a mole after comparing it with the TBP.

A significant association was found between the use of TBP and having received instructions on SSE from a nurse or doctor ($p < 0.05$). No association was found between the use of TBP and the annual frequency of SSE ($p = 0.289$). The strongest association among the psychological variables was found for reported confidence in being able to detect changes in moles. Participants who felt confident in detecting changing moles were more likely to use the CD with TBP when performing SSE ($p < 0.001$).

DISCUSSION

With a rapidly increasing incidence rate of melanoma worldwide there is a need to improve secondary prevention strategies. Several studies have shown that most melanomas are detected by patients, their partners and families (13–16). With easy access to the Internet, today's generation wants to be actively involved in their health surveillance. Numerous studies have shown the effectiveness of CSE, but only a dozen studies have investigated the effectiveness of SSE (7, 16–27). The sensitivity and specificity of SSE is 25–88% and 57–97%, respectively (28). The Dutch Melanoma Guideline (4) advises performing routine CSE as well as SSE on individuals at high risk of developing melanoma. To our knowledge, there is no literature on patients' experiences with and acceptance of the use of TBP. We sought to examine these features among our patients at high risk of developing melanoma.

Even though almost all participants were aware that early detection of melanoma leads to a better prognosis, only half indicated finding regular SSE useful. Of the participants, 77.1% reported performing SSE at least once in the past year. However, only 31.3% reported an adequate frequency of SSE performance of at least once every 2 months, as advised by the Dutch Melanoma

Guideline (4). Other studies among patients at high risk of developing melanoma showed similar percentages; Kasparian et al. (17), Bowen et al. (19) and Mujumdar et al. (20), respectively, found that 21%, 22% and 17% of their patients with a previous history of melanoma performed thorough SSE at least once every 2 months.

We found several factors associated with the frequency of SSE: a personal history of melanoma, having a partner, using a (hand)mirror, feeling confident in detecting new and changing moles, and the patient's own risk perception and anxiety. These factors have also been reported in previous studies (16, 18, 21–25). The correlation values are small and we cannot explain the behaviour of this entire population. However, we can explain the behaviour of our "high performers" when it comes to frequency of SSE. The correlation values explain why our "high performers" are high performers, and why they differ from the others in the group. For example, they are more confident in being able to detect new moles. If we were able to increase this confidence in our "low performers", this would most likely lead to an increase in their frequency of SSE.

Regarding the patients' perceived usefulness of TBP, we found an association with the doctor's decision to excise or not to excise a mole after comparison with TBP ($p < 0.05$ and $p < 0.05$, respectively). Patients who indicated that their doctor had used TBP in this manner also reported a higher frequency of SSE over the past year.

Many of our patients indicated not performing SSE because of their numerous pigmented skin lesions. Of these patients, 81.3% had numerous atypical naevi. Another important reason for patients not to perform SSE was regular CSE. In fact, 78.9% of our patients preferred CSE over SSE. This assumes that patients would rather leave screening for skin cancer up to "the experts".

Access to one's personal TBP was considered unnecessary in a large group of our participants and only a quarter of our participants indicated ever using TBP. These numbers were low, partly because patients indicated feeling ashamed of the TBP, but mainly due to the fact that patients were not sure how to use TBP. We found that patients were more likely to use TBP during SSE when they had had proper information and training on how to do so. In the same way, patients were more likely to perform regular SSE after receiving extensive information on how to recognize melanoma. Therefore it is important that we continue to educate our patients on how to perform SSE and how to use TBP and to remind our patients of the benefits for their health.

The present study has several limitations. The findings are based on participants' self-reports and are thus limited by the accuracy of such data. Patients were examined only after they had received a CD with total body photographs. Therefore, no comparison can be

made between the frequency of SSE before and after the availability of a CD. Also, it is likely that those who did return questionnaire data are performing SSE on a more regular basis, and that they are more likely to use their TBP compared with those eligible patients who did not return questionnaire data. Therefore, percentages of use and usefulness of TBP among our participants may be higher than among the entire patient group. However, a strong point of our study is that all patients who underwent TBP received their total body photographs, regardless of their risk factors for developing melanoma, making our study sample representative for the entire patient population undergoing TBP.

We expect that self-examination in general, not only in dermatology, will become more important in future healthcare. To take full advantage of this trend we need to identify the factors that can improve the efficacy of these multimedia tools.

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