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Need for patient education and better physician-patient communication in melanoma patients: Behaviors and knowledge of melanoma patients

Melanom hastalarının melanom hakkında eğitim ve daha iyi hasta-hekim iletişimi ihtiyacı

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Abstract

Background and Design: Melanoma is a serious type of cancer. Patients previously diagnosed with melanoma are at an increased risk of a second melanoma. Therefore, it is important to know and apply preventive measures. This study aimed to examine melanoma patients' behaviors of sun protection and skin self-examination (SSE), knowledge on risk factors, and communication with their physicians about the disease.
Materials and Methods: A questionnaire-based cross-sectional study was conducted in 65 melanoma patients to assess knowledge of melanoma and sun protection and determine SSE attitudes and patient-physician communication.
Results: Sun exposure was a well-known melanoma risk factor (67.7%), but the knowledge level on other risk factors, especially regarding skin, hair, and eye color phenotypes, was low (between, 21.5% and 36.9%). Sunscreen use practice was insufficient (33.8%) and mostly inadequate. The most commonly reported reason for not using sunscreen was not having a habit of sunscreen use (83.7%). Compliance with other sun protection behaviors was variable. Half (50.8%) of the melanoma patients reported that they perform SSE. The most commonly reported reasons for not performing SSE was not knowing its necessity (71.8%). More than one-third (35%) of patients stated that they did not receive information about melanoma from their physicians. Almost all patients who received information from their physicians were informed verbally, and only 4% received written information.
Conclusion: Our study highlights the need for a comprehensive education for patients about all aspects of melanoma and strategies to improve patient-physician communication. Barriers to preventive behaviors in melanoma patients may be determined in more detail in larger future studies and the content of education may be planned accordingly.
Keywords: Melanoma, knowledge, sun protection, skin self-examination, communication

Öz

Amaç: Melanom en ciddi kanser tiplerinden birisidir. Hastada geçirilmiş melanom öyküsü olması, yeni bir melanom oluşumu açısından risk faktörüdür. Bu nedenle koruyucu önlemlerin bilinmesi ve uygulanması melanom tanısı alan hastalarda önem arz etmektedir. Bu çalışmada, melanom tanısı alan hastaların melanom risk faktörleri hakkında bilgi düzeyleri, güneşten korunma ve kendi kendine deri muayenesi yapma alışkanlıkları ve hekimleri ile melanom hakkında iletişimlerinin değerlendirilmesi amaçlanmıştır.
Gereç ve Yöntem: Kesitsel olarak planlanan çalışmamıza, melanom tanısı alan 65 hasta dahil edilmiştir. Hastalara melanom risk faktörleri, güneşten korunma ve kendi kendine deri muayenesi yapma alışkanlıkları ve hasta-hekim iletişimi hakkında sorular içeren bir anket verilmiştir.
Bulgular: Güneş maruziyeti rölatif olarak iyi bilinen (%67,7) bir risk faktörü olarak saptanırken, diğer risk faktörleri; özellikle deri, saç ve göz rengi hakkındaki bilgi düzeyi düşük (%21,5 ile %36,9 arasında) bulunmuştur. Güneş koruyucu krem kullanımının yetersiz olduğu (%33,8) ve güneş koruyucu kremlerin uygun şekilde kullanılmadığı saptanmıştır. Diğer güneşten korunma alışkanlıklarının uygulanmasının değişken olduğu görülmüştür. Melanom hastalarının yarısı (%50,8) kendi kendine deri muayenesi yaptığını ifade etmiştir. Kendi kendine deri muayenesi

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yapmayan hastalar, yapmamalarının en sık nedenini "kendi kendine deri muayenesi yapmamız gerektiğini bilmiyorduk" olarak belirtmişlerdir. Hastaların üçte birinden fazlası (%35) kendi doktorlarından melanom hakkında bilgi almadıklarını ifade etmişlerdir. Doktorlarından bilgi alan melanom hastaların tamamına yakını sadece sözlü olarak, %4'ü ise yazılı olarak bilgi aldıklarını belirtmişlerdir.

Sonuç: Çalışmamız, melanom hastalarının melanom hakkında kapsamlı bir eğitime ve melanomlu hasta-hekim iletişimini geliştirmeye yönelik planlamalara ihtiyaç olduğunu göstermektedir. Yapılacak daha geniş çaplı çalışmalarla, melanom hastalarının, koruyucu alışkanlıkları uygulamama nedenleri daha ayrıntılı olarak belirlenebilir ve elde edilen sonuçlarla eğitimlerin içeriği planlanabilir.

Anahtar Kelimeler: Melanom, bilgi düzeyi, güneşten korunma, kendi kendine deri muayenesi, iletişim

Introduction

Melanoma is an important cause of skin cancer-related deaths[1-3]. The incidence of melanoma is increasing worldwide, particularly in the United States, European countries, and other Caucasian-populated countries[1,4]. A remarkable increase in the frequency of melanoma has also been recently reported in Turkey[5]. There are well-established risk factors for developing melanoma, such as exposure to ultraviolet, phenotype of light skin, family history of melanoma, and presence of dysplastic nevi[1]. Moreover, patients previously diagnosed with melanoma are at an increased risk of a second melanoma[6-8]. Considering these risks, it is of great importance that melanoma patients have positive attitudes and behaviors toward sun protection and skin self-examination (SSE) and high knowledge level of melanoma risk factors.

In literature, there is an increasing number of studies assessing melanoma patients' preventive behaviors and knowledge of disease conducted in different populations[6,9-16]. However, to our knowledge, no studies have examined these issues in melanoma patients in Turkey. In this article, we will review the results of the survey conducted on melanoma patients in a tertiary university hospital. This study aimed to examine melanoma patients' sun protection and SSE behaviors, knowledge of risk factors, and physician communication about melanoma.

Materials and Methods

An electronic search of the dermatology and medical oncology database of the Trakya University Faculty of Medicine was performed, and data on patients older than 18 years who were diagnosed with melanoma or under follow-up care for melanoma between January 1st, 2017, and September 1st, 2019, were extracted. A total of 155 melanoma patients were found. Patients were contacted by telephone, and they were informed about the goal of the study and invited to participate. Of patients, 20 refused to participate, 15 were deceased, and 55 were unreachable. The final sample size was 65 patients. The study excluded patients with non-cutaneous melanoma and melanoma of unknown primary. We examined the previous literature[11,13,17-21] and developed a questionnaire according to the content of the study as there is no reliable Turkish questionnaire suitable for this study. The questionnaire was applied to participants under the supervision of the dermatologists conducting the study. The study was approved by the Local Ethics Committee of Trakya University Faculty of Medicine (approval number: 08/05, date: 07.05.2018). Written informed consent was obtained from all participating patients.

Demographic characteristics

Demographic characteristics and clinical data including hair and eye color, Fitzpatrick skin type, age at diagnosis, melanoma stage at diagnosis, and subtype, location, and family history of melanoma were collected. Perceived risk of melanoma recurrence or new melanoma development was assessed using a Likert rating scale (much less/about the same/much more/I don't know). Perceived seriousness for melanoma was assessed using a numeric rating scale (NRS; 0 = not at all severe and 10 = extremely severe).

Knowledge on melanoma risk factors

The patients were asked to answer 10 items for the assessment. Questions included the presence of multiple freckles or moles, type of hair (light colored), color of eyes (green or blue), exposure to the sun, history of sunburns, personal history of melanoma or other skin cancers, and family history of melanoma and suspicious nevi. Response options were "yes," "no," and "I don't know."

Sun protection behaviors

Patients were asked about their sun protection practices, including sunscreen use with sun protection factor 30 (yes/no), the season they use sunscreen, the timing of sunscreen application before sun exposure (shortly before/before 15-30 minute/at least 1 hour before), and the reapplication of sunscreen (yes/no). If the participant cited not having used sunscreen, they were asked for their reasons with multiple choices possible: I love tanning/Using sunscreen is difficult/I do not like sunscreen use/Sunscreen is expensive/Sunscreen smells bad/I do not have the habit of using sunscreen/other. Patients were also asked about the frequency of wearing a hat, long sleeves, and sunglasses and seeking shade when exposed to the sun using a Likert rating scale (always/often/sometimes/rarely/never).

SSE practices

To assess SSE practices, patients were asked the following questions: "Do you perform SSE?" (yes/no), "How often did you examine your whole body from head to toes in the past year?" (never/once/two or three times/bimonthly/once in a month/many times per month), "Do you examine your body skin totally naked?" (yes/no), "Do you use a mirror when examining your whole body skin?" (yes/no), "Do you get help from someone to examine back, posterior of neck and buttocks?" (yes/no), "Do you examine your palms and soles?" (yes/no), "Do you carefully examine your nevi?" (yes/no), "If you do not examine your whole body skin what are the reasons? (I do not know the necessity of SSE/I do not know how to do SSE/SSE is difficult/I think SSE is not important for melanoma diagnosis/I prefer my physician to make skin examination/other).

Patient-physician communication

We asked the patients "How much information was given by your physician about melanoma?" to assess communication between patients and physicians using a Likert rating scale (not at all/slightly/moderately/very/extremely). Communication about sun protection behaviors was evaluated with questions asking whether the physicians

recommended the patients to use sunscreen regularly and wear long sleeves and hats on sunny days (yes/no). Patients were also asked whether their physicians provided information on how to perform SSE and whether they were shown a picture or video demonstrating SSE (yes/no).

Statistical Analysis

Data obtained from the questionnaires were analyzed with IBM SPSS Statistics version 24. Numerical variables were shown as mean ± standard deviation and categorical variables as percentages of the population.

Results

A total of 32 (49%) female and 33 (50%) male patients completed the questionnaire. The mean age of melanoma patients was 60.8 years (women: 59, and men: 62.7 years). The characteristics of melanoma patients are summarized in Table 1. Stage two was the most frequent melanoma stage at the time of diagnosis (47.7%). Nodular melanoma was the most common melanoma type (44%). Over half (56%) of the patients had no disease at the time of the survey.

Assessment of knowledge on melanoma risk factors is presented in Table 2. Using NRS, the perceived seriousness of melanoma was 6.4 points on average.

The sun protection behaviors of patients are summarized in Table 2. Among patients who do not use sunscreen, the first three reported reasons were not having a habit of using sunscreen (83.7%), using

Table 1. Characteristics of melanoma patients

	Mean ± SD (range)	n	%
Age (years)	**60.89±13.4 (32-90)**	**-**	**-**
Gender			
Female	-	32	49.2
Male	-	33	50.8
Disease duration (month)	33.6 (1-130)	-	-
Fitzpatrick skin type			
Type 1	-	18	27.7
Type 2	-	39	60
Type 3	-	8	12.3
Eye color			
Blue	-	16	24.6
Green	-	13	20.0
Brown		36	55.4
Hair color			
Red	-	1	1.5
Blond/fair	-	13	20.0
Light brown	-	17	26.2
Dark brown	-	16	24.6
Black	-	18	27.7
Positive family history of melanoma	-	1	3
The first person to notice the melanoma			
Himself/herself	-	51	78.5
Family member friend	-	7	10.8
Dermatologist	-	3	4.6
Physician other than a dermatologist	-	4	6.2
Duration to consult a doctor for melanoma (month)	**7.4±11.1 (1-48)**	**-**	**-**

SD: Standard deviation

Table 2. Knowledge on melanoma risk factors, sun protection behaviors, and skin self-examination practices of melanoma patients

	n	%
Knowledge on melanoma risk factors		
- Sun exposure (yes)	44	67.7
- Susceptibility to sunburn (yes)	41	63.1
- Multiple sunburns (yes)	40	61.5
- Multiple nevi (yes)	33	50.8
- Personal history of melanoma (yes)	31	47.7
- Blonde (yes)	24	36.9
- Family history of melanoma (yes)	24	36.9
- Congenital nevus larger than 20 cm (yes)	23	35.4
- Personal history of non-melanoma skin cancer (yes)	19	29.2
- Red hair (yes)	17	26.2
- Green/blue eyes (yes)	15	23.1
- Multiple freckles (yes)	14	21.5
- Perceived risk for melanoma recurrence/new melanoma development	22	33.8
Sun protection behaviors		
- Sunscreen use (yes)	22	33.8
- Applying sunscreen 15-30 minute before sun exposure (yes)	12	18.5
- Reapplying sunscreen during the day (yes)	5	7.7
- Using sunscreen in all seasons (yes)	4	6.2
- Shade seeking (always/nearly always)	56	86.2
- Hat use (always/nearly always)	33	50.8
- Long-sleeve shirt use (always/nearly always)	28	43.1
- Sunglasses use (always/nearly always)	20	30.8
SSE practices		
- Performing SSE (yes)	33	50.8
- Performing SSE bimonthly/once in a month/many times per month	22	33.8
Compliance to SSE*		
Performing SSE totally naked (yes)	30	90.9
Performing SSE with mirror (yes)	31	93.9
Performing SSE the help of someone (yes)	26	78.8
Performing SSE by examining palms and soles (yes)	31	93.9
Performing SSE by examining existing or new nevi (yes)	28	84.8

*Results based on the patients who stated that they perform SSE (n=33)
SSE: Skin self-examination

sunscreen is difficult (16.2%), and do not like using sunscreen (16.2%). SSE practices of patients are shown in Table 2. Among melanoma patients who do not perform SSE (49.2%), the most commonly reported reasons were not knowing the necessity of SSE (71.8%) and how to perform SSE (46.8%).

Of patients, 64.6% stated that their physicians informed them about melanoma. Of patients, 29% reported that they received information from a dermatologist and 35.3% from a physician other than a dermatologist. The most common source of information other than physicians was the Internet (23.07%). Details on patient-physician communication about melanoma, sun protection, and SSE are presented in Table 3.

Table 3. Communication between melanoma patients and their physicians

	n	%
Informed about melanoma by the physician slightly/moderately/very/extremely (yes)	42	64.6
The way of information transfer		
- Verbal information (yes)*	41	63
- Written information (yes)*	3	4.6
Physician-patient communication about sun protection measures		
- Physician recommended sunscreen use (yes)	30	46.2
- Physician recommended wearing long sleeves and long pants (yes)	24	36.9
- Physician recommended wearing hat (yes)	27	41.5
Physician-patient communication about SSE		
- Physician informed about the necessity of SSE (yes)	35	53.8
- Physician verbally informed about how to perform SSE (yes)	21	32.3
- Physician showed a picture or video demonstrating SSE (yes)	2	3.1

*Multiple answers possible, SSE: Skin self-examination

Discussion

To our knowledge, this is the first study to evaluate the knowledge of disease and protective measures among patients with melanoma in Turkey. Overall, the results of this study show that patients have insufficient knowledge on melanoma risk factors, inadequate sun protection and SSE behaviors, and poor physician communication.

We categorized the melanoma risk factors to better evaluate the knowledge level. The only category in which more than half of the patients (61-67%) responded correctly was sun exposure. Similarly, in studies examining personal attributions for melanoma risk in melanoma survivors, sun exposure was the most frequently reported risk attribution[22,23]. Sun exposure was a well-known risk factor in our study; however, the ratio of correct answers to other melanoma risk categories (presence of multiple moles, personal and family history of melanoma, personal history of non-melanoma skin cancer, and features of phenotypes) was lower than 50%. Especially, the lowest ratio of correct answers about phenotypical characteristics is worrying because although most patients had Fitzpatrick skin type 1 or 2 in our study population, they were unaware that their phenotypical characteristics were risk factors for melanoma. In a French nationwide survey[15] conducted in the general population, the knowledge level about the abovementioned melanoma risk factors was distinctly higher, varying between 64% and 93%. Considering that our study was conducted in melanoma patients, it is obvious that our melanoma patients have a noticeable insufficient knowledge about those risk factors. Moreover, perceived risk of recurrence or new melanoma development and perceived seriousness of the disease were not high. These results indicate the need for education of patients on melanoma risk factors and the seriousness of the disease.

In literature, the most commonly investigated sun protection behavior is sunscreen use[6,9-15,24]. The sunscreen use in our patients (33%) was strikingly lower than in patients in Australia (84%)[25], Canada (72%)[24], the USA (45-69%)[9-11,13,16], and Spain (49%)[12]. We also examined the reasons for the low use of sunscreen in our patients, and the vast majority of patients stated that they did not have the habit of sunscreen use (83.7%). This result shows that although sun exposure was a well-known risk factor, the importance of sunscreen use for sun protection was not well comprehended. Some studies investigated sunscreen use in different populations in Turkey, and the prevalence of sunscreen use was 44.7% and 55.9% in healthy populations[26,27], 40.3% in primary care patients[28], and 34.7% and 46.3% in dermatology outpatient clinics[29,30]. Since these studies have not investigated melanoma patients, direct comparisons with their results cannot be made. However, we expected a greater salience of sunscreen use in our melanoma patients, but the ratio (33.8%) was lower and did not exceed those reported in the general population in Turkey. Although speculative, this result can be explained by the regional educational situation of different regions. The abovementioned studies in healthy populations were conducted in some of the biggest and developed cities of Turkey: Ankara, İzmir, Kayseri, and Mersin[26-28,30]. Therefore, individuals participating in those studies may have a higher educational level, resulting in higher sunscreen use.

Additional questions to evaluate the appropriate use of sunscreen revealed that a great majority of melanoma patients did not apply sunscreen the right way. The appropriate use of sunscreen was evaluated in only a few studies[12,14,16], and unfortunately, it was significantly lower in our melanoma patients. Only 7.7% of the patients applied sunscreen more than once a day, whereas reapplication was reported in 71% and 63% in studies from the US[16] and Spain[12], respectively. In addition, only 6.2% of melanoma patients applied sunscreen for the entire year, and almost half of them did not apply sunscreen 15-30 min before sun exposure. Taken together, the insufficient and inadequate sunscreen use reported by our melanoma patients shows that they possessed little knowledge about appropriate sunscreen use. Moreover, engagement in other sun-protective practices (protective clothing and accessory use) was also lower in our study than previous studies[11-13,16,24,25], with only one exception: The shade seeking (86.2%), which alone is not enough for sun protection. Overall, our findings indicate the need for comprehensive education about adequate sun protection practices for melanoma patients.

There are currently few studies evaluating SSE in melanoma patients[6]. Assessment of SSE practices has not been studied in Turkish melanoma

patients. In our study, half of the patients stated that they had performed SSE in the past year. Prevalence estimation of SSE may have a wide range due to differences between measurements of SSE practices[6,11,25,31-33]. When the patients were asked without a specific description of SSE, high proportions (59-88%) of SSE practices were determined from previous studies[6,11,25,31-33]. However, when the patients were inquired about a thorough SSE, low proportions (14-33%) of SSE practices were obtained[6,9,13,18,21,34,35]. Similarly, 33% of our melanoma patients performed a thorough SSE (including all body sites) at least once every two months in the past year. Although the frequency of patients performing SSE was 50.8%, the compliance of those who perform SSE was high. The vast majority of the patients conducting SSE reported that they used a mirror, took off all their clothes, examined their palms and soles, and checked for changes in their current nevi, and someone assisted them while performing SSE. These results may indicate that melanoma patients who have knowledge about SSE understood its importance and, therefore, applied it correctly. Robinson et al.[36] found that melanoma patients who were assisted by their spouses were significantly more likely to perform SSE. Therefore, the assistance of someone may be important for higher efficacy of SSE[36]. Among all melanoma patients in our study, 43% reported that they examined their palmar and plantar regions when performing SSE, which is comparable with previous studies (27.8-59%)[11,13,19,21]. Examination of palmar and plantar regions should not be overlooked, as acral melanomas have a poor prognosis associated with late diagnosis. Therefore, early detection of acral melanomas can be life saving[37].

In our study, the prevalence of patients who stated that they did not perform SSE at all was (49.2%) was significantly higher than a multicenter study (24.1%)[38] and previous studies conducted in Australia (3.8%)[25], Canada (12.2%)[31], the USA (12.3%, 19.3%, and 41%)[21,32,34,35], and Romania (23.5%). When the reasons for not performing SSE were investigated, more than two-thirds of patients reported that they did not know the necessity of SSE, and half reported that they did not know how to do SSE. The importance of a comprehensive SSE was emphasized in the study by Berwick et al.[39], which revealed that SSE was associated with 63% decrease in melanoma-related mortality. The fact that more than three-quarters of the patients noticed melanoma themselves in our study supports the importance of SSE. Moreover, melanoma patients have an increased risk of a new or recurrent melanoma[35]. Consequently, regular practicing of SSE may help early detection of new lesions for melanoma patients, and early treatment of suspicious lesions can be life saving[35]. Moreover, SSE is recommended by various organizations working on melanoma[3,40]. Therefore, SSE practice is essential in the follow-up process of melanoma patients. So, all patients should be given education on the necessity of SSE and how to perform SSE[6,11,19,21,25,34,38].

An important result of our study was that more than one-third of patients (35%) stated that they did not receive information about melanoma from their physicians. Only a small number of patients (15%) stated that they were moderately or very well informed (data not shown). Moreover, our results also revealed that patients were not provided with adequate information regarding SSE and sun protection methods. Previous studies have suggested a possibility that although melanoma patients were informed, they were unable to retain the information given because of the stress of the melanoma diagnosis[17,41]. Another explanation is that most physicians have limited time to give detailed information[42]. Regardless, physicians should provide adequate information about all aspects of melanoma and ensure that their melanoma patients understand the given information[17]. In this study, almost all patients who received information from their physicians stated that they were informed verbally. Only 4.6% and 3.1% of patients received written information on melanoma and SSE, respectively. These results are strikingly lower than the results reported in previous studies (52-78%)[17,41,42]. It is important to emphasize the fact that being confused and stressed due to the diagnosis of a malignant disease may prevent patients from understanding and remembering the information given[17,41]. Therefore, we agree that in addition to verbal information given by physicians, written information plays an important role to inform patients[17]. Reading the written information in an environment where patients feel calm and comfortable may be a good method to understand and comprehend the information. This is consistent with a previous study showing that patients prefer to receive information from multiple ways, and although physicians are the first source of preference to receive information on SSE, videos and written information are also sought[17]. Brütting et al.[43], found that melanoma patients were more satisfied with written information than they do with the Internet. Recently, an increasing number of patients use the Internet to gain information about their disease. The Internet was the second source (23%) of melanoma information in our study. However, this result is lower than the previously reported Internet use among melanoma patients varying between 48% and 71%[43,44]. It is also significantly lower than the result of a study conducted in Turkish cancer patients, which has shown that 70% of Turkish cancer patients obtained information from the Internet[45]. Our result may be explained by regional sociocultural behaviors or older age of our melanoma patients.

Study Limitations

Our study has several limitations. First, there is potential non-response bias because of the 42% response rate. Second, there is no validated questionnaire on the study items, so there may be self-report response bias. Third, we have to consider that the sample size is small and there is no control group. Fourth, this study is conducted in a single center in the Thrace region; therefore, our data may not be representative of melanoma patients in Turkey. Multicenter data collection is needed to have a comprehensive knowledge of melanoma patients in Turkey.

Conclusion

Our study revealed a low knowledge level on melanoma risk factors and insufficient and inadequate sun protection behaviors and SSE practices and highlighted the need for a comprehensive education in all aspects of melanoma. Education should especially focus on risk factors other than sun exposure. However, although sun exposure was a well-known risk factor, the patients' low level of sun protection habits should be examined thoroughly. The importance of performing SSE should be emphasized more. Larger future studies, particularly focusing on barriers to sun protection and SSE practices, will help plan the content of educational programs. Moreover, strategies for better communication between physicians and melanoma patients are needed, which will positively contribute to the follow-up care of melanoma patients.

Ethics

Ethics Committee Approval: The study was approved by the Local Ethics Committee of Trakya University Faculty of Medicine (approval number: 08/05, date: 07.05.2018).

Informed Consent: Written informed consent was obtained from all participating patients.

Peer-review: Externally peer-reviewed.

Authorship Contributions

Surgical and Medical Practices: S.S.S., H.Y., İ.Ç., Concept: S.S.S., H.Y., Design: S.S.S., H.Y., Data Collection or Processing: S.S.S., H.Y., İ.Ç., Analysis or Interpretation: S.S.S., H.Y., Literature Search: S.S.S., H.Y., İ.Ç., Writing: S.S.S., H.Y.

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