# Racial and ethnic disparities in melanoma awareness: A crosssectional survey



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**Background:** Hispanics are among the fastest growing population in the United States and are predicted to account for one third of the nation by 2060. Although melanoma is more common among white patients, Hispanic individuals are at greater risk of late-stage diagnosis, increased tumor thickness, and poorer survival.

**Objective:** To better understand public awareness of melanoma and evaluate change over the last 21 years, particularly among high-risk minority populations.

*Methods:* A cross-sectional survey collecting information on knowledge and awareness of melanoma was conducted on 285 participants from May through November 2017.

**Results:** Approximately 39% of participants were unaware of melanoma. Sixty-five percent successfully identified early signs of disease. Approximately 86% of Fitzpatrick skin types (FST) I and II identified melanoma as a cancer, compared to 46.3% of FST III and IV and 57.6% of FST V and VI. Hispanic participants were less likely to know what melanoma was compared to white participants (odds ratio [OR], 0.27; 95% confidence interval [CI], 0.65-0.11; P = .0037). US natives (OR, 2.38; 95% CI, 5.56-1.04; P = .0403) and patients with any college education (OR, 2.86; 95% CI, 5.26-1.54; P = .0007) were more likely to know the meaning of *melanoma*.

*Conclusion:* White participants and those with any college education were more likely to know the meaning of melanoma. Individuals of racial and ethnic minorities would benefit from educational programs geared toward early detection. (J Am Acad Dermatol 2020;83:1098-103.)

*Key words:* health disparities; melanoma; melanoma awareness; patient comprehension; patient education; skin cancer.

utaneous melanoma accounts for the majority of skin cancer deaths in the United States, and its incidence has been continuously rising over the last several decades. In the United States alone, it was estimated that nearly 100,000 new cases of melanoma were diagnosed in 2019, and 7230 people died of the disease. Despite representing less than 5% of all cutaneous malignancies,

melanoma remains the most lethal skin cancer.<sup>3</sup> Although melanoma most commonly affects white individuals, Hispanic individuals, one of the fastest growing populations in the United States, are disproportionately affected by greater morbidity and mortality rates when diagnosed.<sup>4,5</sup> According to the US Census Bureau, the term *Hispanic* is used to refer to anyone of Spanish, Cuban, Puerto Rican, or South or

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Central American descent.<sup>6</sup> Hispanic individuals diagnosed with melanoma are more likely to have thicker primary tumors, later stages of disease, and distant metastases when compared to non-Hispanic white patients.<sup>5</sup> Poor prognosis in Hispanic patients is likely multifactorial and may be secondary to lack of knowledge or misconceptions about melanoma

risk, atypical presentation, impaired access to care, and language barriers, ultimately resulting in a delay in diagnosis.<sup>4</sup>

The current standard of care for diagnosing melanoma remains periodic skin examination performed by a clinician with pathologic confirmation of the melanoma. According to the US Preventive Services Task Force, there is insufficient evidence to formally recommend that individuals perform skin self-examinations (SSEs); however, SSEs

could, in theory, aid in detecting melanoma at an earlier stage and, hence, reduce morbidity and mortality.8 It is therefore imperative that the general public be educated on melanoma and the importance of its early detection.9 In 1996, Miller et al2 studied public awareness of melanoma in the United States as well as knowledge of melanoma-specific risk factors and early signs of disease.<sup>2</sup> Their study found deficiencies in the general public's knowledge of and attitude toward melanoma, as well as the practice of SSE. Their results supported the need for better public education about melanoma. In the past 2 decades, there have been several public health efforts to increase melanoma awareness, including Melanoma Monday and Melanoma/Skin Cancer Detection and Prevention Month, both sponsored by the American Academy of Dermatology. We conducted a survey with questions regarding melanoma emulating the questions by Miller et al<sup>2</sup> to better understand current public awareness of melanoma and evaluate change over the last 21 years, particularly among high-risk minority populations.

#### **METHODS**

This study was approved by the Boston University institutional review board. A survey was conducted from May 2017 to November 2017 among 285 participants aged 18 years or older, recruited from outpatient dermatology clinics at Boston Medical Center and East Boston Neighborhood Health

Center. Verbal consent was obtained for all eligible participants. Consented participants were asked to complete an approximately 5- to 10-minute questionnaire that included questions on knowledge regarding characteristics and risk factors associated with melanoma. Privacy was permitted to minimize the Hawthorne effect.

### **CAPSULE SUMMARY**

- This study evaluated public awareness of melanoma.
- Deficits in melanoma knowledge and awareness improved among US natives, white individiuals, and those with some college education, yet it has remained largely unchanged in minority populations over the past 2 decades.
- Individuals of ethnic minorities may benefit from tailored educational programs geared toward early detection.

The questionnaire was designed to emulate the questionnaire used by Miller et al in 1996.<sup>2</sup> Our questionnaires were available in both English and Spanish, with direct Spanish translation from English questionnaires by 2 fluent Spanish-speaking providers. Participant demographics, including age, sex, self-identified ethnicity, education level, and annual income, as well as physiciandetermined skin type, were collected. Skin type was evaluated by asking participants their skin's reaction to sun

exposure (*After sun exposure, your skin always burns, burns then tans, rarely burns, never burns?*) and by physician evaluation. The questionnaire included questions regarding awareness of the term *melanoma*, knowledge of risk factors, early signs, and common body sites of melanoma (supplemental materials; available via Mendeley at <a href="https://doi.org/10.17632/h5gcpmk5nh.2">https://doi.org/10.17632/h5gcpmk5nh.2</a>). Data collection were performed using RedCap (Nashville, TN). Responses from our surveys were then compared to the responses recorded by Miller et al<sup>2</sup> in 1996.

Data collected were all categorical and are shown as n (%) in our tables. A multivariable logistic regression model predicting patients who claimed to not know the meaning of melanoma was subsequently derived. We a priori selected the variables: race, education, gender, birth country, and age. In this model, white race was used as the reference, education was dichotomized to *any college education* versus *none*, and birth country was dichotomized to *US born* versus *not US born*. SAS, version 9.4 (SAS Institute, Cary, NC) was used for all statistical analyses.

## **RESULTS**

Of the 285 participants surveyed, 59.6% were female, and participants had a mean age of  $45.6 \pm 17.8$  SD years. For race, 46% identified as Hispanic/Latino, 36% as non-Hispanic white, 8% as

#### Abbreviations used:

SSE:

CI: confidence interval FST: Fitzpatrick skin type OR: odds ratio

skin self-examination

black, 7% as Asian American, and 11% as other race, nonspecified. Fifty-five percent had completed a high school education or less, and 40% reported an income of less than \$34,999/year (Table I). Most (72%) white participants were determined to be FST I or II by dermatologist evaluation, 89% of Hispanic participants were FST III or IV, and 100% of African

#### Melanoma awareness and knowledge

American respondents were FST V or VI.

When asked, "Can you tell me what melanoma is?", nearly 55% of respondents identified melanoma as some kind of skin cancer, 6% knew it was some kind of cancer, and the remaining 39% were unaware of the term. When asked to identify factors that would increase the risk for developing melanoma, approximately two thirds of participants were able to identify at least 1 risk factor. Of these risk factors, 54% of respondents recognized bistory of sunburn as a risk factor, whereas bad sunburns in childhood was identified by only 19% of participants. Affirmative responses were relatively infrequent for other risk factors, including family history of melanoma (34%), fair skin (20%), having lots of moles (19%), being born with moles (8%), freckles (7.4%), and red hair and blue eyes (6%). When asked to name the early signs of melanoma, 65% were able to identify specific signs of early melanoma (ie, a change in mole or a new mole). Participants also named several other skin changes as early signs of melanoma, many of which were nonspecific (eg, any type of change in the skin or redness). When asked where in the body melanoma was most likely to occur, 46% answered anywhere exposed to sun, with only 12% of participants including the frequently covered areas of the back, chest, and abdomen. Table II details participants' responses to our melanoma awareness survey relative to the responses recorded in 1996 by Miller et al.<sup>2</sup>

# Variations in knowledge according to sociodemographic factors

Awareness of the term *melanoma* and knowledge that it is a type of skin cancer was lowest among men, Hispanics, and those with a high school education or less. Knowledge of melanoma appeared to progressively increase with rising income levels.

Table I. Patient demographics

Patient demographics (N = 285)	Value
Sex, n (%)	
Male	115 (40.4)
Female	170 (59.6)
Race/ethnicity, n (%)	
White	102 (35.7)
Black	23 (8.0)
Hispanic/Latino	131 (45.9)
Asian American	19 (6.6)
Other	11 (3.8)
Education, n (%)	
High school graduate or less	156 (54.7)
Some college or more	129 (45.3)
Income, n (%)	
<\$34,999/y	114 (40.0)
\$35,000-\$50,000/y	29 (10.2)
\$50,000-\$100,000/y	36 (12.7)
>\$100,000/y	16 (5.6)
Prefer not to answer	90 (31.5)
Age, y, n	
<25	21
25-44	141
45-64	71
≥65	52
Fitzpatrick skin type, n	
I	6
II	82
III	74
IV	89
V	24
VI	9

Knowledge and awareness of melanoma differed across FST. Most respondents with FST I and II (86.5%) were aware that the term *melanoma* referred to a cancer, and 77.5% knew it was specifically a type of skin cancer. In contrast, approximately half of participants with FST III or IV (46.3%) and FST Vor VI (57.6%) were aware of melanoma as a cancer, and only 43% knew it was specifically a type of skin cancer (Table III).

In our multivariable analysis, we found that Hispanic pariticpants were less likely to be aware of what melanoma was compared with white participants (odds ratio [OR]; 0.27, 95% confidence interval [CI], 0.65-0.11; P = .0037) (Table IV). Conversely, US-born patients (OR, 2.38; 95% CI, 5.56-1.04; P = .0403) and patients with any college education (OR, 2.86; 95% CI, 5.26-1.54; P = .0007) were more likely to know the meaning of melanoma. Other factors, such as sex and age, were not significantly associated with the understanding of melanoma.

**Table II.** Awareness and knowledge of melanoma in patient population

Awareness and knowledge of melanoma (%)			
Awareness and knowledge	Miller et al, <sup>2</sup>		
of melanoma	1996, %	2017, %	
Can you tell me what melanoma is	?		
Some kind of skin cancer	34.1	54.6	
Some kind of cancer	20.5	6.0	
Other	3.7	0.0	
Don't know	41.7	39.4	
Which of the following do you believe	eve can incre	ase risk	
of melanoma?*			
History of sunburn	82.3	54.2	
Bad sunburns in childhood	58.4	19.4	
Having lots of moles	41.3	19.0	
Being born with moles	28.1	8.1	
Fair skin	63.3	20.1	
Red hair and blue eyes	27.8	6.0	
Freckles	21.7	7.4	
Family history of melanoma	67.4	34.5	
Other	0.5	1.4	
None of these, don't know	5.0	34.9	
Can you name early signs of melan-	oma?*		
A change in mole	21.8	43.2	
A new mole	4.5	21.8	
A sore that won't heal	5.1	14.7	
A lump	2.2	9.8	
Any type of change in the skin	4.4	21.8	
Blotchy skin or dark spots	15.0	21.1	
Redness	2.0	10.9	
Discoloration	3.9	14.7	
Skin rash	2.2	9.1	
Dry, itchy, or scaly skin	0.8	8.4	
Other	1.3	0.0	
Don't know	36.7	47.0	
Where is melanoma most likely to o	occur?*		
Head and shoulders	51.7	8.5	
Arms and legs	35.5	8.8	
Chest and stomach	5.4	3.9	
Back	10.3	8.1	
Anywhere exposed to sun	12.3	45.9	
Don't know	17.7	45.2	

<sup>\*</sup>Response categories are not mutually exclusive; participants could choose more than 1 answer.

#### DISCUSSION

Melanoma-specific knowledge appears to have improved among those who were already aware of the disease. Of the respondents who were already familiar with the term *melanoma*, the majority (55%) of them knew it was a type of skin cancer, which constitutes an improvement from 1996 (34.1%). Knowledge of the early signs of melanoma also improved in the past 2 decades, with most (65%) respondents today successfully identifying early melanoma-specific changes (*a change in mole* or *a* 

**Table III.** Awareness of melanoma according to sociodemographic factors: Can you tell me what a melanoma is?

Sociodemographic factors	Type of skin cancer, %	Type of cancer, %	Don't know, %
Overall	54.6	6.0	39.4
By sex			
Female	57.0	6.5	36.5
Male	50.4	5.2	43.5
By race			
White	76.5	7.8	15.7
Black	47.8	17.4	34.8
Hispanic	38.2	2.3	59.5
Asian	57.9	10.5	26.3
By age, y			
18-24	42.9	24	33.3
25-44	51.1	2.8	46.1
45-64	57.1	7.1	35.7
≥65	64.2	5.7	28.3
By Fitzpatrick skin type*			
l or II	77.5	9.0	13.5
III or IV	43.8	2.5	53.1
V or VI	42.4	15.2	42.4
By education			
High school graduate or less	39.7	8.3	51.3
Some college or more	72.0	3.1	25
By income			
<\$34,999/y	51.8	6.1	41.2
\$35,000-\$50,000/y	69.0	6.9	24.1
\$50,000-\$100,000/y	72.2	5.6	22.2
>\$100,000/y	87.5	6.3	6.3
Prefer not to answer	40.4	4.5	55.1

<sup>\*</sup>Given collinearity of Fitzpatrick skin type and race, only Fitzpatrick skin type was included in the regression model.

new mole) compared to a smaller (26%) percentage in 1996.<sup>2</sup> This rise in melanoma-specific knowledge may be explained in part by public health campaigns, such as the National Melanoma/Skin Cancer Detection and Prevention Month (pioneered by the American Academy of Dermatology in 1997). A recent shift in public health approaches to early detection (urging patients to look out for a new or changing skin lesion rather than relying on the ABCDs of melanoma, which can be cumbersome and difficult to remember for the public) may be playing a role in the increased awareness of early signs of disease as well.<sup>9,10</sup> Increasing access to technology and online resources has also helped dismantle barriers to health information since the turn of the new millennium. 11

Race and socioeconomic status were found to be important predictors of melanoma knowledge today. White race and college education were

**Table IV.** Odds of knowing what melanoma is by sociodemographic factors

Variable	Odds ratio (95% CI)	P value
Race		
African American vs white	0.41 (1.25-0.14)	.1177
Hispanic vs white	0.27 (0.65-0.11)	.0037
Asian American vs white	0.56 (1.96-0.16)	.3603
Other race vs white	0.32 (1.35-0.08)	.1207
Born in the United States vs not	2.38 (5.56-1.04)	.0403
Any college education	2.86 (5.26-1.54)	.0007
Female vs male	1.52 (2.70-0.86)	.1477
Age	1.01 (1.03-0.99)	.3672

CI, Confidence interval.

positively correlated with knowledge of melanoma in a multivariate regression model (Table IV). This remains largely unchanged from 1996.<sup>2</sup> Hispanic participants and those born outside of the United States were less likely to know the meaning of melanoma. According to our results, Hispanic individuals have a higher rate of answering don't know to questions regarding melanoma compared to white individuals of the same skin type (40% vs 8.2%; P = .016). Our data suggest that people with fairer skin types (FST I and II) have higher rates of knowledge and awareness of melanoma compared to those with darker skin types (FST III-VI). It is encouraging that those with fairer skin types—and, therefore, higher incidence rates of melanomaappear to be better informed about the disease. However, despite having lower incidence rates of melanoma, darker-skinned patients from ethnic minorities are more likely to be diagnosed with advanced-stage melanoma and have worse survival rates compared with their nonminority counterparts. 12-14 Hispanic ethnicity has been found to be the strongest predictor for high-risk, late-stage melanoma diagnosis, independent of income level, age, sex, or insurance status. 13 It has been shown that Hispanics receive suboptimal skin cancer screenings, with Hispanics receiving 40% fewer full-body skin examinations than non-Hispanic white individuals. 13 Hispanics are additionally less likely to perform SSEs (15% of Hispanic individuals report performing SSE compared to 32% of non-Hispanic white individual). 13,15 This can be attributed to a multitude of factors, including language barriers between patients and providers, impaired access to care, and misconceptions about the low risk of melanoma among Hispanic patients (ie, darkly pigmented individuals are less likely to use sun protection and be aware of personal skin cancer risk.)4,13,16

As the Hispanic population continues to grow within the United States, there have been increasing efforts to educate this population in a culturally relevant way. 17 The role of language and culture in relation to patients' perceptions of skin cancer has been specifically studied in this population, 18 and community-based<sup>19</sup> and online educational programs<sup>17</sup> have since been created to specifically address the needs of Hispanic populations. In 2019, Dayanara Torres, a Puerto Rican former Miss Universe with 1.3 million Instagram followers, announced that she had been diagnosed with metastatic melanoma. Since sharing her diagnosis (in a viral video that has since been viewed more than 869,000 times), New Jersey dermatology clinics have seen an increase in Hispanic patients with concerns about skin cancer, with patients citing Torres's announcement as their motivating factor. Torres's effect on melanoma awareness among Hispanic individuals exemplifies the importance of raising awareness in culturally relevant ways, helping effectively reduce these health disparities.

This study uncovered persistent deficits in melanoma knowledge and awareness in minority populations, despite the public health efforts over the past 2 decades that may have served to educate advantaged white individuals. Our results highlight persistent gaps in basic melanoma knowledge across all ethnicities, including specific risk factors associated with melanoma and body sites to pay particular attention to when performing an SSE. All population groups, irrespective of ethnicity, education, and income, are at some risk of developing melanoma. However, ethnic minorities face greater morbidity and mortality rates when diagnosed with melanoma, which may be partially due to atypical presentation and lack of melanoma awareness. 16,20

Our study limitations include a small sample size and the sampled population being demographically different from the population originally sampled by Miller et al.<sup>2</sup> Most (81%) of Miller et al's sampled population were white, and only 7% were Hispanic,<sup>2</sup> whereas our sampled population was mostly Hispanic (46%) and 36% white, making direct comparison between the studies challenging. The latest census reports the Boston, MA, population as 78% white and the overall US population as 77% white and 18% Hispanic; however, US population projections estimate a 115% increase in the Hispanic population, with 29% of the US population being Hispanic by 2050. 21 White individuals will become a minority, making up 47% of the population by 2050, thus highlighting the need for education in Hispanic populations, given their projected make up of more than one quarter of the US population.<sup>21</sup>

Furthermore, the term *Hispanic/Latino* comprises a heterogeneous group of multicultural individuals with varied degrees of skin types; however, the majority of respondents who identified as Hispanic or Latino included in this analysis had FST III or IV.

In conclusion, despite more than 20 years of melanoma education, a racially and socioeconomically diverse real-world patient population in 2017 has the same understanding of melanoma as it did in 1996. Our results support a need for better public educational programs, particularly those populations. 4,20 toward minority Educational programs that are culturally relevant and include specific sections for skin of color have been shown to better promote early melanoma detection in individuals of ethnic minorities and may help decrease the ethnic disparities in melanoma-related mortality.<sup>20</sup> At the patientphysician level, dermatologists may educate their patients, including Hispanic patients, should they choose to perform SSEs to specifically inspect the extremities and acral areas, given the higher incidence rates of melanoma on those areas in this population.<sup>16</sup>

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