

# **The Delayed Diagnosis and Poor Prognosis of Melanoma in People of Color**

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On my honor as a University Student, I have neither given nor received unauthorized aid on this assignment as defined by the Honor Guidelines for Thesis-Related Assignments

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## Introduction

Melanoma is the deadliest form of skin cancer because of its ability to spread, or metastasize, to other parts of the body. This cancer originates from the melanin-producing cells of the skin, called melanocytes. Melanin is a natural pigment that absorbs harmful ultraviolet (UV) rays (Gupta et al., 2016). Melanoma is about 20 times less common in people of color (POC) because they produce more photoprotective melanin. Although POC are less likely to be diagnosed with melanoma, their prognosis is significantly worse than their white counterparts (Goss et al., 2014). Despite the introduction of new technologies such as immunotherapies and targeted therapies, the discrepancy in diagnosis and consequent prognosis is only getting worse (Qian et al., 2021). Why do POC have a delayed diagnosis and poor prognosis compared to their white counterparts and why is the discrepancy continuing?

Melanoma can be characterized as (1) localized, meaning the cancer has not spread beyond the skin where it started, (2) regional, meaning the cancer has spread to structures or lymph nodes nearby, or (3) distant, meaning the cancer has spread to distant parts of the body including vital organs. Early detection and intervention are associated with improved outcomes (Conic et al., 2018) because the cancer is less likely to have metastasized. POC are more likely to present with an advanced melanoma (regional or distant), severely hindering their survival rates. The American Cancer Society (ACS) estimated the relative survival rate for localized, regional, and distant melanoma to be 99%, 68%, and 30%, respectively (*Melanoma Survival Rates | Melanoma Survival Statistics*, n.d.). Therefore, a delayed diagnosis is conducive to a worse prognosis. More broadly, black patients are 1.5 times more likely to die from melanoma than their white counterparts (K. Buster, 2019). By 2050, the United States (US) Census Bureau predicts that the US population will be fifty percent Hispanics, Asians, and

African Americans (Gupta et al., 2016). Thus, it is crucial to raise awareness of melanoma to POC to protect the *entire* US population. Putting the factors relevant to the disparity into context with each other will allow for a more comprehensive understanding of the problem and will aid in future initiatives to eliminate disparities in malignant melanoma.

### Literature Review

Several studies have been integral to understanding the disparity between POC and white patients' experience with melanoma. The National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) registry “collects and publishes cancer incidence and survival data from population-based cancer registries covering approximately 48.0 percent of the U.S. population” (*Surveillance, Epidemiology, and End Results Program*, n.d.). SEER is a critical database that is used in many studies regarding melanoma. Qian et al. analyzed the ongoing racial disparities in melanoma, specifically how it has persisted since 2010 (Qian et al., 2021). Qian used the SEER database to conclude that racial disparity in MSS is worsening despite improving treatment options. Ward-Peterson authored the study which identified differences in survival by race/ethnicity among US melanoma patients, taking stage and site at diagnosis into account (Ward-Peterson, 2016). Finally, Byrd et al. related the advanced disease presentation with the consequent worse prognosis (Byrd et al., 2004). Together these studies form the basis of understanding what the discrepancy is and why it persists. However, factors such as family history of melanoma, follow-up time, socioeconomic status (SES), insurance status, and comorbidities are not included in the SEER database. The following argument corroborates these studies and provides a basis for understanding this disparity.

### Methods

The factors relevant to melanoma diagnosis timelines in POC can be analyzed using actor-network theory (ANT). ANT attempts to “‘open the black box’ of science and technology by tracing the complex relationships that exist between governments, technologies, knowledge, texts, money and people” (Cressman, 2009, p. 3). In this case, the black box represents the network of actors that cause a delayed diagnosis and poor prognosis in POC (*Figure 1*). To open the black box is to understand the complexities of the network. In order to open this black box, the most prominent actors were identified and classified into three categories: biologic, socioeconomic, and cultural. Actor-network theory identifies actors by their relationships with other actors in that network. Therefore, actors affect other actors’ identities and actors are inherently related. The identity of actors and the relationships between actors create the network responsible for the delayed diagnosis and poor prognosis of melanoma in POC.

Biologic, socioeconomic, and cultural actors were identified by extracting information from diagnosis and survival trends, statistics regarding the state at diagnosis and the overall outcome, and educational resources for training physicians. Inherent to these data were demographic factors illuminating the discrepancy. Results of the aforementioned studies along with historical and cultural contexts allow for a more complete picture. The goal of compiling and analyzing these data was to identify the factors that contributed most to the delayed diagnosis, and consequent poor prognosis, of melanoma in POC.



Figure 1. Schematic of the application of Actor-Network Theory

### Actors

## Biologic

### *Melanocytes*

POC are less likely to get melanoma because of their melanocyte count. Melanin protects the skin from harmful UV rays. POC have more melanin-producing melanocytes which offers them more protection from these rays. Since they are more protected, they are less likely to develop melanoma. However, this creates a false security for POC and their physicians when it comes to melanoma prevention.

Due to the visual nature of diagnosis, the amount of melanin in the skin of POC can also make it difficult for patients and physicians to detect (*Figure 2*) (Wang et al., 2015). Wang et al. found that medical students were less likely to order a biopsy for POC. This was attributed to two errors: (1) medical students did not identify the melanoma and (2) medical students underestimated the possible severity of the melanoma. Medical students set the future standard of care; if they are failing to recognize melanoma in POC, this disparity will only be exacerbated.

### *Anatomical Locations*

Melanoma in unusual anatomical sites are more common in minorities and results in delays, underdiagnosis and melanoma-specific mortality at a 1.96- to 3.01-fold greater risk (Cormier et al., 2006).

Melanoma that appears in the palms of the hand, soles of the feet, and under the nails is called Acral lentiginous melanoma (ALM) and is an independent negative predictor of survival (Gumaste et al., 2014). ALM, which is often detected late, is more common in minorities than

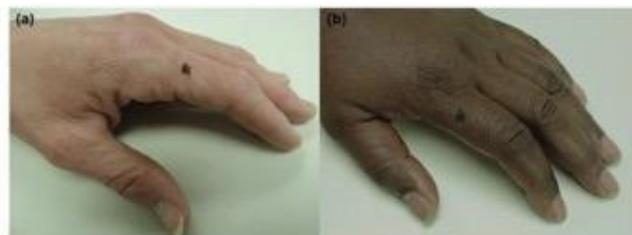


Figure 2. Training materials for medical students to diagnose melanoma on (a) light and (b) dark skin tones. Photo courtesy of Wang et al. (Wang et al., 2015).

non-hispanic white (NHW) patients because POC have a biological predisposition to ALM. POC are also more likely to have melanoma in the lower extremities and trunk area (not sun exposed) so it's often overlooked (Myles et al., 2012). When coupled with the following actors, the anatomical predisposition for melanoma in unusual locations for POC lessens the likelihood of early detection.

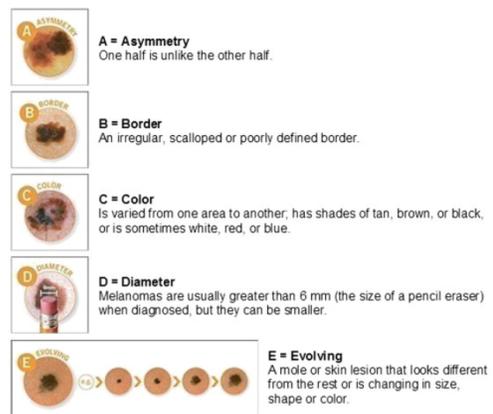
## Socioeconomic

### Melanoma Education

POC are less likely to be educated on the risk factors associated with its occurrence. Lack of awareness is a risk factor for POC to have a more advanced diagnosis. If these populations don't know what to look for (self-screening) and what to do if something seems off, they won't be able to get care at the earliest stage possible. Asymmetry, border, color, diameter, and evolution (ABCDE) is a common mnemonic used to detect melanoma.

However, the resources outlining this strategy for self-examination are mainly geared towards white populations (Figure 3). Race and socioeconomic status were found to be important predictors of melanoma knowledge today (Sanchez et al., 2020). For example, public health initiatives may not have effectively reached the Hispanic population (Qian et al., 2021).

### Access



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Figure 3. Melanoma Educational Pamphlet (*Early Detection of Melanoma: Reviewing the ABCDEs - Journal of the American Academy of Dermatology*, n.d.) showcasing melanoma indicators on various white skin tones.

Access to treatment is also lesser in this population, not only to physicians who can diagnose, but also to the cutting edge therapies responsible for curing this disease. Overall, there is a shortage of dermatologists, including dermatologists of color, an unequal geographic distribution of physicians across the nation, and insurance limitations that make getting care more difficult for POC (Pritchett et al., 2018). While access to skin cancer clinics for POC specifically has not been addressed in the literature, this factor is bound to have a negative impact on mortality because if you cannot get diagnosed, you cannot get treated.

### *Income and Insurance*

Unfortunately, SES and insurance status are important determinants of access to timely quality care (Ward et al., 2008). Insurance status plays a role because it is associated with time from diagnosis to definitive surgery (Qian et al., 2021). Adamson et al. found that non-white race was an independent risk factor for delayed treatment of six weeks or longer (Adamson et al., 2017). This means that all else equal, non-whites will have delayed treatment. Additionally, those who are uninsured are less likely to receive preventative care/education for diseases such as skin cancer (*Health Insurance and Access to Care*, n.d.). Preventative care and education would greatly improve outcomes because of the disease's association with time; if caught early enough, the cancer cannot metastasize.

POC, along with patients with Medicaid and lower incomes are less likely to receive immunotherapy, a cutting edge treatment for metastatic melanoma. Although immunotherapy usage is escalating, not all populations are experiencing this rise equally. Because immunotherapy utilization is expected to amplify even further in the future, these public health and economic issues are essential to identify and address for POC (Haque et al., 2019). Income

and insurance are correlated with access to these treatments because of access, geographic, and cultural associations.

## **Cultural**

### *Clinical Trial Representation*

POC are consistently underrepresented in clinical trials (ex: CheckMate-067 and CheckMate-037 included <0.7% African Americans and <1.1% patients of Asian descent) (Bristol-Myers Squibb, 2021). Reasons for this include mistrust of research, lack of access to research due to geographic constraints, culturally-incompetent research designs, lack of sufficient information, low SES and associated deficiencies of insurance (Spears et al., 2011). Knowledge of the Tuskegee Study of Untreated Syphilis continues to contribute to the mistrust in research and the possibility of unethical studies (Katz et al., 2008). Since treatment options are most successful for the population they are tested on, POC are less likely to have effective treatment. Newer research shows how the practice of extrapolating data obtained from lighter skin types has led to a gap in provider and patient understanding of melanoma in skin of color (Patzelt & Vashi, 2021). Many factors contribute to the mistrust in healthcare that POC have, and underrepresentation is only one factor that proliferates this disparity.

### *Physician Awareness*

Dermatology textbooks don't often show POC as examples in care processes (Onasanya & Liu, 2021). In a survey of textbooks assigned at top medical schools, imagery of six common cancers for POC or dark skin tone was non-existent (Louie & Wilkes, 2018). A common misperception in both the public and some segments of the medical community is that patients with darker skin tones and certain racial/ethnic origins are not at risk for skin cancer (Hu, 2011).

This dangerous assumption puts POC at risk for inadequate/infrequent screenings. Melanoma screenings are performed at a suboptimal rate on black and Hispanic patients. This disparity in screening lowers the frequency of early detection in minority populations, which could then lead to later stage incidence (Dawes et al., 2016). As emphasized previously, later stage melanoma has a higher likelihood of metastasis and higher rates of mortality (*Cancer Facts & Figures 2014*, n.d.). Care-provider education presents an actionable opportunity for growth in mitigating the disparity.

Since melanomas are rare in POC, medical students and primary care physicians have limited opportunities to see melanoma in darker skin tones, especially during the short clinical rotations that are part of their general training. Notably, “in a recent U.S. survey, 47% of dermatologists and dermatology residents reported that their medical training (medical school and/or residency) was inadequate in training them on skin conditions in blacks” (K. J. Buster et al., 2012). Consequently, medical educators have few opportunities to teach and assess medical students’ ability to diagnose melanoma in this population (Wang et al., 2015). Further, lack of knowledge of the varying risk factors for melanoma in POC compared to their white counterparts is indicative of an incomprehensive medical education. This need has become so great that Art Papier, a dermatologist from Rochester, NY, wrote the book and accompanying online decision support system *VisualDx: Essential Dermatology in Pigmented Skin* (Papier et al., 2005). Papier, a white dermatologist, believes that “we can fix this problem today by having health systems and medical and nursing schools teach the skin exam in people of color to reduce error and bias; train clinicians about specific treatments for diseases that occur more often in patients of color; and advance tools and education that position clinicians to provide excellent care for every patient.” (“To Begin Addressing Racial Bias in Medicine, Start with the Skin,” 2020). This initiative

represents a step in the right direction. However, due to the overarching disregard for melanoma in POC, diagnostic delay is still observed.

### *Patient-Physician interactions*

Patient-physician interactions also govern the quality of care. Matching the patient and physician's race, called racial concordance, is associated with better communication quality, information-giving, patient participation, and participatory decision-making (Shen et al., 2018). As of 2018, the percentages of Asian, Black, and Hispanic doctors was 17.1 percent, 5 percent, and 5.8 percent, respectively (*Figure 18. Percentage of All Active Physicians by Race/Ethnicity, 2018*, n.d.). These three groups comprise 27.9 percent of active physicians. With the minority population in the US rising rapidly, the possibility of racial concordance is becoming even more difficult. The lack of racial concordance for melanoma patients is detrimental to their outcomes because melanoma is diagnosed visually. Physicians are less familiar with skin tones that don't resemble their own. Thus, the demographic of physicians affects the patient-physician interaction which affects the care given to POC.

### Analysis

It is impossible to pinpoint any one of these actors as the *most* influential because they affect people at varying degrees. Although it is more difficult to diagnose melanoma in POC biologically, socioeconomic and cultural actors exacerbate the discrepancy in care. POC should not be penalized for their inherent melanin count and photoprotective properties. For this to happen, progressive strides in socioeconomic and cultural actor categories must be made.

Intersectionality represents the forces that work together to create a person's unique experience, whether that be disadvantaged or privileged. It combines socioeconomic and cultural

factors to decide how society treats us. Socioeconomic and cultural factors are “outward,” meaning they can’t be controlled by the individual. In a broader sense, this means that the people who are not affected by this discrepancy are responsible for mitigating it. ANT revealed that although the biological aspects of the black box cannot be addressed directly, the socioeconomic and cultural aspects can. Specifically, the cultural actor category is the most vulnerable because of its dependence on society. Society creates the norms that drive the culture. This means that, as a society, we can have a real impact on the outcome of the black box.

These actors work in a positive feedback loop. For example, a cultural emphasis on cancer treatments has led to the introduction of immunotherapy to treat melanoma. For those who can afford it, this is positive. However, for those with a lower SES, outcomes worsen relative to the population and the disparity grows. As the positive feedback loops between biological, socioeconomic, and cultural actors increase, the effects of disparities in any of these categories are compounded. Therefore, instead of tackling the actor that is most prevalent, future work should include minimizing the positive feedback loop that these actors present.

POC can’t control where melanoma shows up and how it is viewed by a physician. However, as a society, we *can* control how we consciously treat those who don’t look like us. We *can* increase the spread of information to at-risk populations. We *can* train the next generation of doctors to have a wider understanding of melanoma in all skin types. We *can* encourage and recruit POC to be involved in clinical trials and feedback groups. This multifaceted problem does not have one solution, it has many that must work together.

## Conclusion

It is imperative to recognize the relationships of various actors and their roles in discrepancy in care. As the black box has been opened, multiple segments of this discrepancy were revealed, each deciding the fate of the patient. It is possible to identify the actors that present problems with actionable solutions. Thus, socioeconomic and cultural actors must be addressed in order to mitigate this disparity. It is not feasible to alter the biological actors because they are inherent. Future work on this topic could include finding/creating actionable solutions to address the problems presented in the socioeconomic and cultural actor categories.

ANT was used as a framework to analyze the disparity in diagnosis and prognosis for POC. While three major categories were identified through a rigorous literature review, it is possible that other influential factors contribute to the disparity. These unpublished actors should also be sought after; the best way to do this would be to talk to the people experiencing this disparity. First-hand accounts will likely expound the discrepancy further as these voices are the ones not heard enough in medicine.

### Keywords

Melanoma-specific survival (MSS) - mortality and morbidity associated with melanoma prognosis, not relating to comorbidities involved

Advanced diagnosis/presentation - in a later stage of development, has spread beyond where it began

Diagnosis - identification of the present disease

Prognosis - prediction of the course of the disease aiding in the determination of treatment and outcome

POC - people/person of color, any non-white person, defined by the American Academy of Dermatology (AAD) as “diverse skin colors and includes people of African, Asian, Latino, Mediterranean, Middle Eastern, and Native American descent” (*Skin Cancer in People of Color*, n.d.).

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