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## DERMATOLOGY | REVIEW ARTICLE

# Health disparities in mycosis fungoides

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**Abstract:** Mycosis fungoides, the most common form of cutaneous T-cell lymphoma, has a higher incidence and poorer prognosis in African-Americans. The factors that may be contributing to this disparity are presented in the context of a health disparities framework that includes discussion of patient-related factors such as race/ethnicity, socioeconomic status, and biological differences, provider-related factors such as patient-provider communication and the competing demands for providers' time, and health care system-related factors such as access to health care and workforce diversity. The changing demographics of the USA emphasize the need to understand and address health disparities in mycosis fungoides and other dermatologic diseases. The framework presented here can be used to examine disparities in other dermatologic conditions and advance health disparities research in dermatology.

**Subjects:** Cutaneous Oncology; Dermatology; Medicine

**Keywords:** mycosis fungoides; cutaneous T-cell lymphoma; ethnic skin; skin of color; health disparities; dermatology

### 1. Introduction

The National Institute on Minority Health and Health Disparities (NIMHD) defines health disparities as “differences in incidence, prevalence, morbidity, mortality and burden of diseases and other adverse health conditions that exist among specific population groups.”(Collins & Ruffin, 2013). Health disparities are complex and multi-factorial, and are often linked to social and economic disadvantages. They originate from dynamic interactions of genetic, biological, environmental, social, economic, and psychological factors.

### ABOUT THE AUTHOR

Ginette A. Okoye is an assistant professor of Dermatology and director of the Johns Hopkins School of Medicine Department of Dermatology's Ethnic Skin Program. The Ethnic Skin Program focuses on diseases that disproportionately affect people with pigmented skin and Dr. Okoye is specifically interested in health disparities in dermatology. This paper is the first in the literature to examine health disparities in mycosis fungoides and is hopefully the beginning of a worthwhile discourse about health disparities in dermatology.

### PUBLIC INTEREST STATEMENT

Mycosis fungoides is the most common T-cell lymphoma of the skin and, for unknown reasons, it is more common and more severe in black patients. This paper discusses possible explanations for this difference, including the contributions of genetics, socioeconomic status and access to health care, and interpersonal communication between patients and health care providers. Differences in outcomes of diseases among different racial/ethnic groups have been well described in many different types of cancer, but it has never been described in skin lymphomas. This paper is the beginning of this discussion and will hopefully lead to further research in this area as we seek to design interventions to improve outcomes in black patients with mycosis fungoides.

The US Department of Health and Human Services has identified the elimination of health disparities as a top priority; yet, the most recent annual Agency for Healthcare Research and Quality (AHRQ) National Health Disparities Report (NHDR) shows continued evidence of health disparities among people of different racial and ethnic groups and in individuals of lower socioeconomic status (SES) (National Healthcare Disparities Report, 2012). Although health disparities in dermatology are a growing area of interest (Alghothani, Jacks, Vander Horst, & Zirwas, 2012; Buster, Stevens, & Elmetts, 2012; Hernandez, Robin, & Mermelstein, 2009), there are limited data on this important topic. Disparities in several dermatologic diseases have been identified, including atopic dermatitis (Janumpally, Feldman, Gupta, & Fleischer, 2002; Shaw, Currie, Koudelka, & Simpson, 2011), melanoma (Bradford, Goldstein, McMaster, & Tucker, 2009; Byrd, Wilson, Hoyler, & Peck, 2004; Wu et al., 2011), sarcoidosis (Cozier et al., 2011; Swigris et al., 2011; Westney & Judson, 2006), and cutaneous lymphoma (Bradford, Devesa, Anderson, & Toro, 2009; Criscione & Weinstock, 2007; Hinds & Heald, 2009; Imam, Shenoy, Flowers, Phillips, & Lechowicz, 2013; Sun et al., 2009; Wilson, Hinds, & Yu, 2012; Zampella & Hinds, 2013). This paper initiates a dialog about disparities in dermatology in the context of cutaneous lymphoma, and provides a framework with which to think about disparities in dermatology in general.

There is a growing body of evidence that disparities exist in mycosis fungoides (MF), the most common type of cutaneous T-cell lymphoma (CTCL). MF is classically described as a disease of middle-aged white men that presents with arcuate, poikilodermatous patches, and plaques on sun-protected areas of the body such as the buttocks and intertriginous areas (Hinds & Heald, 2009). In black patients, MF often presents differently from the classical descriptions, with polymorphic pigmentation and secondary lichenification. In these patients, MF is frequently misdiagnosed as atopic dermatitis, tinea versicolor, and vitiligo (Hinds & Heald, 2009). Additionally, MF in black patients is characterized by higher incidence, more advanced disease stage at presentation, younger age at diagnosis, and worse survival when compared to other races (Bradford et al., 2009; Criscione & Weinstock, 2007; Hinds & Heald, 2009; Imam et al., 2013; Sun et al., 2009; Wilson et al., 2012; Zampella & Hinds, 2013). Notably, black women who present before age 40 may be more likely to present with advanced stage disease, experience disease progression despite treatment, and may be more likely to die from their disease when compared to white women (Sun et al., 2009). The incidence rate of MF in blacks has been reported as 9.0–10.0 per million person-years compared to 6.1–8.1 per million person-years in whites (Bradford et al., 2009; Criscione & Weinstock, 2007). The range of the average age at diagnosis for blacks with MF is 45.3–51.5 years compared to 54.8–59.2 years in whites (Wilson et al., 2012; Zampella & Hinds, 2013). Wilson et al. report that blacks were more likely to present with advanced disease (defined as T3 or T4 disease), and in a study done by Sun et al., 33% of black women were diagnosed with advanced disease (Stage IV) vs. 8% of white women (Sun et al., 2009; Wilson et al., 2012). Furthermore, black race was found to be a predictor of worse survival with a hazard ratio of 1.78 and the two-year relative survival risk in blacks is 89% compared to 96% in whites (Imam et al., 2013). The reasons underlying these striking differences are unknown, and are likely multi-factorial.

The major complexity of studying health disparities is the challenge of discerning the reasons behind the differences in susceptibility or prognosis of different population groups. One mechanism for understanding a newly described health disparity is to identify the potential roles of the patient, the provider (and the interaction between the two), and the health care system (Kilbourne, Switzer, Hyman, Crowley-Matoka, & Fine, 2006).

## 2. Patient-related factors

### 2.1. Genetics

With the exception of specific genes attributed to diseases such as sickle-cell anemia and cystic fibrosis, differences in genetic makeup have not yet been found to explain health disparities among individuals of different races/ethnicities (Kilbourne et al., 2006). Although one study showed a link between specific HLA class II alleles and familial MF, no genetic factors have been definitively linked

to the development, progression, or response to treatment of MF (Hodak et al., 2005). However, recent studies suggest that genetic differences by race/ethnicity may predispose some individuals to specific dermatologic diseases. For example, specific HLA-B alleles have been linked to an increased risk for carbamazepine-induced Stevens Johnson Syndrome/Toxic Epidermal Necrolysis (SJS/TEN) in some Asian populations (Cheung et al., 2013). These findings suggest that there may be a role for genetic studies focused on health disparities in MF and other dermatologic diseases that determine individual disease susceptibility using meaningful genetic markers instead of race/ethnicity.

### **2.2. Race/ethnicity**

Race/ethnicity is not a biologic construct. It is a social construct that represents underlying social and cultural factors, not necessarily genetic similarity (Horn & Beal, 2004). Nonetheless, people are categorized by race, and race-related differences in health outcomes do exist. We have described some of the disparities in outcomes in black patients with MF. These disparities in incidence, prevalence, and prognosis by race can also be seen in other cutaneous diseases such as atopic dermatitis, melanoma, and sarcoidosis (Byrd et al., 2004; Shaw et al., 2011; Westney & Judson, 2006). Risk factors such as diet, occupational exposures, educational status, and SES have all been linked to the development and subsequent morbidity related to these diseases (Byrd et al., 2004; Cozier et al., 2011; Janumpally et al., 2002; Shaw et al., 2011; Swigris et al., 2011; Westney & Judson, 2006; Wu et al., 2011). Race may actually act as a surrogate for these social and cultural determinants (Horn & Beal, 2004), and exploring these factors may improve our understanding of the poorer health outcomes of minority populations in some dermatologic diseases.

### **2.3. Education and socioeconomic**

It is well accepted that educational level and SES play a role in health and health outcomes. Poor health literacy and accessibility to medical care are barriers that may impact diagnosis and prognosis. The National Library of Medicine defines health literacy as “the degree to which people have the capability to obtain, process, and understand basic health information and services needed to make appropriate health decisions.” (Nielsen-Bolman, Panzer, & Kindig, 2004). We have improved health education for common conditions such as hypertension and within the field of dermatology, significant progress has been made with the melanoma education campaign, the “ABCDEs of melanoma.” With a relatively uncommon skin cancer such as MF, it may be more difficult to increase awareness of the disease and impact outcomes, especially with African-Americans who generally have a low perceived skin cancer risk (Pichon, Corral, Landrine, Mayer, & Adams-Simms, 2010).

Access to health information and health care providers are obstacles that compound a patient’s capability to understand health issues. Access to specialists such as dermatologists is limited for some patients. African-Americans have greater prevalence of poverty, low income and lack of insurance (McMichael & Jackson, 2000). For patients with insurance coverage, insurance type can impact accessibility. In one study comparing appointment accessibility for dermatologists in Ohio, privately insured patients were more likely to get appointments and wait a shorter time for their appointment when compared to patients with public insurance (Algothani et al., 2012).

### **2.4. Beliefs**

Values and beliefs can be rooted in cultural traditions or history, or as a result of perceptions that may have arisen from a lack of adequate health information (Kilbourne et al., 2006). The myth that blacks do not get skin cancer is an example of the latter. Among African-Americans, there is a misperception that the sun protection afforded by dark skin is absolute and that skin cancer is strictly related to sun exposure (Battie, Gohara, Verschoore, & Roberts, 2013). However, it is well known that some types of cutaneous malignancies are related to other factors such as chronic inflammatory diseases, human papilloma virus infection, and non-healing wounds (Battie et al., 2013). Certainly, MF is not related to sun exposure; in fact, ultraviolet light is a commonly used treatment modality in this disease. Several studies have cited misperceptions about the risk of skin cancer in skin of color, which lead to worse outcomes including increased mortality (Battie et al., 2013; Buster, Zhiying, Fouad, & Elmets, 2012; Pichon et al., 2010). Health care access and lack of education may contribute

to the development of these beliefs, but a patient's perception of their risk for skin cancer can also be influenced by personal or family experiences such as a history of skin cancer and history of sun sensitivity (Pichon et al., 2010).

In addition to misperceptions and false beliefs, the value placed on seeking specialty care affects the time to diagnosis and treatment and subsequently, affects health outcomes. In a study on minority perceptions and barriers to seeking dermatologic care, 50% of the patients surveyed preferred to see their primary care doctor (instead of a dermatologist) and 26% ignored their dermatologic problem (Aina, 2009). In MF, a disease in which the clinical presentation can be quite subtle, patients may minimize the significance of the pigmentary changes or consider them to be "cosmetic" concerns. As a result, they may ignore the skin changes or they may choose to see non-dermatologist providers, among whom misdiagnoses of dermatologic conditions are likely to be more common (McMichael & Jackson, 2000).

### 3. Provider-related factors

#### 3.1. Knowledge and attitudes

Incorporating education on skin of color during dermatology training has improved, but it is still limited, especially in less diverse geographic areas (Nijhawan, Jacob, & Woolery-Lloyd, 2008). As previously mentioned, MF can have unique presentations in skin of color that can be overlooked or misdiagnosed. Cutaneous lymphoma is an uncommon skin cancer, and the training to recognize its signs and symptoms may not be adequate. Primary care physicians are usually first-line providers, especially if there are socioeconomic barriers to a specialist. Research has shown that their ability to recognize even common dermatoses is not as proficient as their dermatology-trained counterparts (McMichael & Jackson, 2000).

Another factor to consider is provider bias based on personal prejudices, culturally influenced myths, and stereotypes that may affect treatment decisions. This is not necessarily ill-willed and may even be unconscious, but studies have shown that biases do occur and may influence care received by minority patients (Moskowitz, Stone, & Childs, 2012; Shavers et al., 2012). For example, the perception of lower SES may influence the type of treatment a patient is offered. Several studies have shown that African-American Medicare patients are less likely to receive common procedures or needed more aggressive treatments due to lack of early diagnosis, poor initial care, or poor chronic disease management (Williams, 1999). A recent study demonstrated that blacks with advanced stage MF were less likely than whites to receive treatment with extracorporeal photopheresis, an expensive but effective treatment modality with minimal side effects (Agi, Kuhn, Chung, Zampella, & Hinds, 2015). Confounding factors such as SES and insurance status may be blamed for these differences, but even when SES and health care access are accounted for, minorities are more likely to receive lower quality care when compared to whites (Williams, 1999).

#### 3.2. Communication and trust

The patient-provider dynamic plays a significant role from encounter initiation to subsequent follow-up. A key component to that relationship is communication. Mistrust, delayed treatment decisions, and ultimately worse outcomes can result from inadequate communication. This breakdown in communication is one of the limiting factors for minorities seeking dermatologic care. Their perception is that they "will not be taken seriously" (Aina, 2009) and their concerns will not be addressed. By fostering a "shame-free environment" (Misra-Hebert & Isaacson, 2012) that is open to discussion and feedback, trust can develop within the patient-physician relationship. Subsequently, patients may be more willing to divulge more history, comply with treatment recommendations, and follow-up appropriately. In an uncommon disease like MF with a chronic course and potentially complicated treatment decisions, the patient-dermatologist relationship can be vital to patients' confidence in their diagnosis and treatment plan and adherence to the latter.

### **3.3. Competing demands**

In a fee-for-service system with limitations on the amount of time provided for each patient encounter, providers may be at a disadvantage when it comes to providing the best care for their patients. Overbooked clinics with set time slots may jeopardize the provider's ability to take the time to obtain a detailed history and perform appropriate diagnostic testing (such as skin biopsies). Additionally, the cost imposition that insurance prior authorizations for procedures such as biopsies place on physicians is an estimated \$80,000 per full-time equivalent physician (Morley, Badolato, Hickner, & Epling, 2013). These time-consuming insurance prior authorizations may preclude physicians from accepting insurance plans that require authorizations, or may encourage a higher threshold for performing a biopsy on suspicious cutaneous lesions/rashes. In some dermatology practices, patients are asked to return on a later date for their biopsy while the application for prior authorization is processed. This may result in further delays to diagnosis and increase the risk of losing patients altogether if they fail to return for their biopsy.

## **4. Health care system-related factors**

### **4.1. Accessibility to dermatologic care**

The organization of the health care system in the USA can cause barriers to specialized care, especially for minorities. In a survey looking at possible obstacles to obtaining dermatologic care in minorities, issues of insurance coverage, cost of care, and access were the most common concerns (Aina, 2009). Access may be difficult for lower income individuals who depend on publicly funded programs, and whose insurance may not be accepted by some dermatologists. For patients for whom private insurance is available, co-pays for specialty physicians may be quite high. Patients with MF are seen frequently in follow-up, and phototherapy, the most common treatment option for MF, is administered up to three times per week. These costs can quickly become prohibitive for patients with high co-pays.

In 2008, the number of dermatologists in the USA was 3.6 per 100,000 persons, (Kimball & Resneck, 2008) suggesting insufficient access to dermatologic care, especially in rural areas. According to the Cutaneous Lymphoma Foundation website, cutaneous lymphoma treatment centers exist in only 25 states (Treatment Centers, n.d.). At these centers, patients obtain comprehensive care for their MF and have access to new and experimental therapies.

Even when patients are able to see a dermatologist, other factors such as availability of treatment or cost of medications may be additional barriers. For example, phototherapy (often first-line treatment for early stage MF), total skin electron beam radiation therapy, and extracorporeal photopheresis (two treatment modalities used in more advanced MF) are not readily available in some geographic areas. Many of the topical and systemic medications used in MF are expensive and have no generic equivalents. This is a barrier for patients with no prescription coverage, those with prescription coverage but limited formularies, and those who pay a percentage of their prescription costs.

### **4.2. Workforce diversity**

There is emerging evidence that racial concordance between physicians and patients plays an important role in the perception of care, which affects patient outcomes (Johnson, Powe, Roter, & Cooper, 2011). The patient-provider relationship is strengthened by mutual understanding and the impression of having corresponding goals. One study found that time spent with the physician was longer and patient satisfaction was higher in physicians and patients of similar racial background (Cooper et al., 2003). Improving interracial communication and education is needed, but until that gap can be bridged, increasing the number of minority physicians may enhance patient-provider interactions. Additionally, expanding the number of minority physicians also impacts the type of patients cared for. It is well established that minority physicians are more likely to treat minority patients and work in communities with lower SES (Kington & Carlisle, 2001). If physician access is easier, patient encounters are longer, and more trusted and engaging communication is held

between doctor and patient, perhaps there will be improvement in the diagnosis, treatment, and prognosis of MF. Diversity in the dermatology workforce is still a work in progress. Caucasians comprise 78% of the dermatologists in the USA, Asians 13%, Hispanics 5%, and African-Americans 4% (Castillo-Page, 2010).

## 5. Conclusion

We have described several factors in the contexts of the patient, the provider, and the health care system in an attempt to understand their roles as contributors to the health disparities seen in MF and in the field of dermatology in general. As with most health disparities, it is the complex interactions of biological, social, and health system factors that impact the health outcomes seen in minority patients with MF. The framework suggested here can be applied to other dermatologic diseases with health disparities. Further research is needed to investigate the role of each of these factors, and to identify and implement effective interventions to reduce health disparities in dermatology.

## Abbreviations

NIMHD	National Institute on Minority Health and Health Disparities
NHDR	National Health Disparities Report
AHRQ	Agency for Healthcare Research and Quality
SES	socioeconomic status
MF	mycosis fungoides
CTCL	cutaneous T-cell lymphoma
SJS/TEN	Stevens Johnson Syndrome/Toxic Epidermal Necrolysis

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## Competing interests

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