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BURNED BEAUTY: STORIES OF HOW BLACK WOMEN BURN SURVIVORS MANAGE THEIR  
TRAUMA AND RECOVERY

BREE MCCALL

60 Pages

This study focuses on an under-researched segment of the burn-survivor community, *Black-women burn survivors*, who tend to go unrecognized beyond the initial observation of physical scarring or disfigurement. Recent data indicates that burn survivors of color, post-injury, report less satisfaction with their appearance and lower levels of community integration when compared to white burn survivors (Mata-Greve et al. 2022). Likewise, men burn survivors fare better than women during the post-injury recovery period when it comes to navigating romantic relationships, social interactions, and work and employment opportunities (Levi et al. 2018). This topic of burn survivors at the race-gender nexus is personal to me, as it is my own story; therefore, I adopt an *emic* or insider approach to this study. My goal is to fill a gap in the literature by centering the mutual race-gender narrative construction of the reality of Black-women as burn survivors.

The beauty standards framed by Eurocentrism centers idealized depictions of white women's physical features while invalidating Black women's physiques and appearances (Strings, 2019). In addition, recent Black appearance standards combat the devaluing of Black women in society, compelling us to acknowledge the visibility of Black women's bodies in definitions of beauty, desirability, brilliancy, and dignity. At the same time, critics rightly caution

against using beauty as a pathway to power for Black women, which would exclude other types of Black faces and bodies, those that do not fit into “respectable” imagery (e.g., disabled bodies). They contend that using beauty as a vehicle to power would commodify Black women’s bodies and reduce them to commercial appeal (Hoboson, 2016). Given these considerations, Black women with burn injuries get passed over in society more often than not, and must fend for themselves, as their appearance in some ways may fall short of *both white and* Black female beauty standards.

This study investigates processes of exploration of the self as compared to societal beauty standards as they have been established by Eurocentrism, the media, and within-group standards. It explores how one reconciles one’s sense of identity and beauty following a traumatic experience, in particular an accident that leaves one with physical and mental scars from burns. Likewise, I consider how disability studies can be incorporated to interpret the experiences of Black women burn survivors, as well as the theme of major life disruption both during the wound healing phase that requires specialized medical care and when healing from trauma after a burn wound that leaves a new normal in its wake. To gather the primary data material for my thesis, I interviewed a sample of five Black women burn survivors recruited online, to better understand their experiences of life after surviving a fire.

KEYWORDS: burn survivor, Black beauty, life disruption, intersectionality, burn trauma, inspiration porn, disability studies, Black feminism

BURNED BEAUTY: STORIES OF HOW BLACK WOMEN BURN SURVIVORS MANAGE THEIR  
TRAUMA AND RECOVERY

BREE MCCALL

A Thesis Submitted in Partial  
Fulfillment of the Requirements  
for the Degree of

MASTER OF SCIENCE

Department of Sociology and Anthropology

ILLINOIS STATE UNIVERSITY

2023

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BURNED BEAUTY: STORIES OF HOW BLACK WOMEN BURN SURVIVORS MANAGE THEIR  
TRAUMA AND RECOVERY

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## ACKNOWLEDGMENTS

I would like to thank all the people who believed in this project and made it a reality. The role of intersectional identity after a life-changing event is territory that has not been adequately tapped into, so thank you for seeing my vision and the call to action to fill in this gap in literature. To my committee, thank you for all the contributions to this research. To my family and friends thank you for the support and encouragement. Last but not least, to my grandma Tici, thank you for being my angel and guiding me through my defense.

B.M.

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## CHAPTER I: INTRODUCTION

Annually, there are “over 480,000 people treated for burns” in the United States (Peters et al., 2021, p. 323). Fifty-nine percent “of those who are admitted and treated are white, whereas the remaining are Black (20%), Latinx (14%), or other non-white populations (7%), with a disproportionate number of Black [people] experiencing burn injuries compared to the general population” breakdown (ibid.). Even when attempts are made to control for insurance status, “Black patients exhibit worse mortality and morbidity after burn injury” (ibid.). Additionally, Black and/or Hispanic (compared to white) “burn survivors exhibit poorer wound healing and worsened community integration and adjustment” after being released from the hospital after burn injury (ibid.). From these statistics we can conclude that Black people and other people of color are exponentially underserved and underrepresented in this very particular trauma response, which then leads to poorer rates of re-integrating back into society.

The purpose of this study is to explore the world of Black women who feel their appearance has been “spoiled” by scarring from burns to their face and/or body. Physical “abnormalities” and or disfigurement after surviving a fire can lead to one’s own sense of feeling impaired and to stigmatization in society, where our perceptions of self and beauty are inadvertently influenced by what others think (Goffman, 1963). Having been a burn survivor myself, I know that it is no easy task to be physically scarred and to journey back to a sense of identity and belonging. Attractiveness is a significant way that human beings get categorized, with limitations to what is socially accepted as “attractive.” To analyze this phenomenon, Ela Pryzbylo and Sara Rodrigues (2018) write in their book, *On the Politics of Ugliness*, that “ugliness or unsightliness is much more than a quality or property of one’s appearance. In

Western contexts and histories especially, ugliness has long functioned as a social category that demarcates one's rights and access to social, cultural, and political spaces" (p. 1). Indeed, the concept of ugliness has long been used as an effective tool to differentiate rights and access to various public spaces, and it is important to note that ugliness is not just a physical property but has a much wider scope in terms of its impact.

Sociologist Heather Laine Talley explored the relationship between what is considered "ugly" and its connections to disability or disfigurement. Being considered conventionally attractive is a "pretty privilege" within itself and beauty appears to be an important factor of gender and race socialization. In her 2014 critical media analysis, "Bullied Teens: 'Ugly' Faces, and Cultural Production of Disfigurement," Talley analyzed the ways in which teens' natural-born faces that are not deemed socially "desirable" are slowly being steered to disfigurement diagnosis by medical professionals. She addresses "the fact that a face that many would perceive as unremarkable, normal, or average can be described and acted upon as 'disfigured,' [which] points to the power of diagnosis to either amplify or moderate stigma" (Talley, 2014, para. 9). Talley's work offers insights into the modern perception of "disfigurement" and its implications for social control. The idea of what is considered a "normal" face is constantly evolving toward increasingly unrealistic beauty ideals, depending on factors such as changing cultural contexts, social media, Face Tune filters and plastic surgery, ratcheting up the pressure on people to conform.

My focus on Black women who are burn survivors is motivated by: 1) my personal connection to the topic (I myself am a burn survivor, and a Black woman); 2) data on emerging differences in trauma care for women of color compared to white women; and 3) the overlap

for women trying to adhere to both Eurocentric *and* Black beauty standards, but not fitting in either. Eurocentric beauty standards have been cultivated by white supremacy and capitalism, influencing what is deemed acceptable and beautiful in society. The sociological definition of the term Eurocentric means “a cultural phenomenon that views the histories and cultures of non-Western societies from a European or Western perspective” (Pokhrel, 2011, p. 321). This premise sets the tone for what is deemed socially attractive in the U.S. and what is not from a European perspective, being that Europeans have forced outsized influence on the Western world. Eurocentric beauty standards imply that all features that are non-Western are not deemed beautiful or considered “ugly.” These features include melanin skin, textured hair, full lips, body curves, and wider noses. Being born with physical features associated with Black people already puts Black women at a disadvantage in the racial caste system of Western societies that intersects with gender inequality.

As a rebuttal to a long history of suppression of Black beauty and features, in more recent years Black women have tried to reframe that narrative. In relation to the Black Lives Matter movement, there has also been a movement in play to celebrate and uplift Black women/beauty called “Black Girl Magic.” While this idea is wonderful and liberating, there are some unforeseen negative implications. This notion of Black Girl Magic is rooted in the politics of respectability; a tool historically used to combat “white supremacist views of the Black body” (Ford cited in Hobson, 2016, p. 4). This has proven to be problematic: while Black people are shining a light on their culture, politics, and all that embodies one’s human dignity, progressive Black people are now creating aesthetic prototypes, leaving the African American image to be interpreted by outsiders on social media, for example, as to what is acceptable corporeality in a

Black woman. Hobson’s argument reveals that the portrayal of Black women in this digital era is contradictory, because “Black beauty has become both an essential and essentialist tool to validate the black body—which has wide repercussions on our inclusive politics that represent the collective body politic” (Hobson, 2016, p. 3). Hobson further argues that if researchers are going to do a Black beauty project, it must be inclusive and intersect race with gender, class, sexuality, body shape & size, and disability, while it must steer away from the commercialization of Black beauty.

My lived experience as a Black woman burn survivor has caused me to wonder about other Black women who share this life-changing experience of being a burn survivor. I acknowledge there is a shared experience after surviving a fire while the healing process afterwards varies among all races and ethnicities; however, I believe the societal standards of appearance as they pertain to Black women is a unique phenomenon and should be incorporated into the limitations of reconciling the experience of U.S. burn survivors into such a Eurocentric world.

My thesis research will examine Black women who are burn survivors trying to navigate a world of beauty standards while having physical differences such as scarring and disfigurement. The research questions I intend to explore in this study are:

1. How do Black women psychologically cope with burn injuries as an under-appreciated trauma?
2. How does a Black woman who has been a burn survivor with physical scarring reconfigure dominant beauty standards so that she can reconcile herself into *dominant societal standards of beauty*?

3. How does a Black woman who has been a burn survivor with physical scarring reconfigure dominant beauty standards established for Black women so that she can reconcile herself into *within-group standards of Black women's beauty*?

In seeking to answer these questions, I will consider the intersection of race, gender, and a form of disability (scarring & disfigurement) that shapes perceptions of beauty and identity, extending the existing literature on burn survivors. A vital focus of this study will be the prominence of other people's perceptions that burn survivors internalize—i.e., the classic theory of the “looking-glass self” coined by sociologist Charles Horton Cooley (1902), that we as social individuals base our sense of self on how others view us. Certainly, seeking validation from others gets heightened when physical scarring and/or activity impairments are involved.

## CHAPTER II: LITERATURE REVIEW

### *The Black Female Survivor and Life Disruption*

As a starting caveat, I will not refer to those affected by burns as “victims” as commonly referenced. The term “victim” carries with it a tone of defeat, succumbing to fatalism surrounding the wounding experience. People who make it out alive from fires are *survivors*, burn survivors. The burn recovery process itself is a very long one. After the traumatic event, if you were conscious the whole time during the burn incident and immediately after like I was, you are in a state of shock, processing what just happened. I remember feeling numb, physically, mentally, and emotionally. I could not conceptualize that something so horrific had just happened to me. I was silent the whole ambulance ride to the hospital. Most survivors are unconscious and have no idea of what happened until they wake up some time later in the hospital when they have been somewhat stabilized. Still, regardless of when you have your “what the hell happened” moment, the same emotions apply. A survivor never forgets the first moment they looked at the absence of their skin, their face, or the worst part in my opinion, if they had to have any fingers, toes, or limbs amputated. Your whole world as you knew it disappears, you feel you are no longer the person you remember being your whole life prior.

To better understand this disruption of life and its implications, various studies have focused on the life-course and how disruption affects identity formation. From a cultural perspective, we are socialized to analyze life in its different phases, and we create expectations of what life “should” be like during those phases (i.e., dating during adolescent/young-adult years, marriage, children, career, retirement, death in the Western heteronuclear model). Anthropologist Gay Becker studied this phenomenon and wrote that “when expectations about

the course of life are not met, people experience inner chaos and disruption to the fabric of their lives. Such disruptions represent loss of the future” (Becker, 1994, p. 383). We all have expectations for our lives, and at the center of this is our physical bodies. Our bodies become the cornerstone of how we create and interpret meaning (Csordas et al. cited in Becker, 1994). Based on Becker's research, we understand the human body to be a meaningful symbol the foundation of social activity. After a physical disruption, all the ways in which we knew life to be according to our understanding of our bodies must be relearned, and this leads to a focus on a new identity, and a “new social order” must be built (Becker, 1994, p. 385).

With any traumatic event, there is the possibility of mental health issues after the accident that include post-traumatic stress disorder, dissociation, depression, and anxiety. In addition, African American women are at a greater risk for exposure to further traumatic events and are less likely to seek mental health services than white women. Consequently, Black females who survive traumatic events tend to have a different experience in dealing with such tough situations. This is because historically and culturally, seeking help for mental health is not widely accepted among African American demographics. Black women tend to report avoidant and passive coping strategies which place them at an increased risk for lower psychological adjustment (Stevens-Watkins et al., 2014) while researchers also report that women who have higher self-esteem and a greater sense of wellbeing tend to cope better with daily life stressors. While I believe this argument to be true, it still neglects the process of building self-esteem and a sense of wellbeing after a *traumatic physical* event that alters a person’s appearance. Black pain and trauma can go unrecognized and unacknowledged in medical settings, or it can become constructed as a problem if attended to by a predominantly white staff. White staff



often try to oversee and control Black recovery practices from trauma, colonizing pain itself. Working against a Black trauma survivor is that “People perceive Blacks as feeling less pain than whites”; therefore, caregivers are less attentive to Black people’s pain and suffering (Hawley & Flint, 2016, p. 31).

### *Intersectionality*

While trying to make sense of all the layers that contribute to the distortion of beauty standards from a Black female burn survivor’s perspective, I believe there is an intersection to dissect. In a college study of Black women and their battle with body image, researchers concluded that “body image and beauty among African American women can only be truly understood within a framework of interlocking systems of ‘isms’ – e.g., racism, sexism, classism, heterosexism” (Stevens-Watkins et al., 2014, p. 540). This introduces the theoretical framework of intersectionality into the scope of beauty standards among Black women. The term “intersectionality” was coined by critical-race feminist Kimberlé Crenshaw, and many scholars adopted this term and expanded upon it. In a TED talk, Crenshaw describes intersectionality as an “individual being impacted by multiple forces, then abandoned to fend for self” (Crenshaw, 2016). Thus, intersectionality describes the simultaneous impact of numerous social forces on an individual and the concomitant lack of support.

Intersectionality refers to an integrative perspective that emphasizes the interconnection of race, several nationalities, gender, sexual orientation, class, and disability. Crenshaw (2016) explains that the conflict of intersectionality leads to a “framing problem.” My interpretation of this TED talk statement as it relates to beauty standards is that there is a foundation or [frame] that was put in place as to what is deemed beautiful, and people with

physical scarring do not fit into that set of ideal appearance norms conditioned by *misogynoir*: “the ways anti-Black and misogynistic representation shape broader ideas about Black women[‘s beauty]” (Bailey, 2021, cover copy). Moreover, there is an underrepresentation or complete invisibility in the literature of Black women who are burn survivors. As mentioned earlier, a reoccurring theme throughout this research project is understanding the dynamics of a burn survivor’s recreation of her own notion of beauty within a limiting frame.

### *Interpersonal Connection*

There are several different domains in which intersectionality of different aspects (e.g., race, gender) can be applied: interpersonal, disciplinary, cultural, and structural. The interpersonal domain focuses on the individual level of interaction, and irons out who is advantaged or disadvantaged within society and interactions (Lopez & Gadsden, 2016). This domain is the most micro-level as it outlines basic social interactions and relationships among Black women burn survivors or their interactions with non-burned people. Altered appearance due to burns can cause stress for the survivor, and research has shown that female burn survivors report greater body image dissatisfaction than male burn survivors (Levi et al., 2018). This dissatisfaction spills over into all areas of life, socially and intimately. Researchers have used the Life Impact Burn Recovery Evaluation (LIBRE) scale to measure social participation for burn survivors. They analyzed data from 601 survivors, and the results show that men scored higher than women on 4 of the 6 scales (Levi et al., 2018). The scales measure sexual relationships, social interactions, work & employment, and romantic relationships. Women have a harder time reintegrating back into society after their accident compared to men. This also goes for romantic relationships as well, meaning women have a harder time entering the

dating scene after the accident compared to males. Studies also show that survivors who attend peer support groups (among other survivors) have a better reintegration back into society (Grieve et al., 2020). In relevance to the subject of power differentials in social interactions, “compared to burn survivors of color, white burn survivors in the U.S. demonstrate better social reintegration over time and are more likely to return to work after their burn injury” (Averton, 2020, para. 14). All this is to say that burn survivors are disadvantaged at the interpersonal level, particularly when race and gender of the survivor are considered.

This interpersonal domain can correlate to burn survivors in how they compare themselves to others; by others, I mean burn survivors making relative comparisons to women who are for one, “unburned”; and two, deemed conventionally beautiful by societal standards and their social identity group’s appearance standards. The way in which birth-assigned females conceptualize beauty starts early in girlhood. Girls are taught gender from the moment they can understand toys, clothing, and television show preferences and being “pretty” requires one to maintain her appearance, i.e., wear nice (feminine) clothes, and act soft and appear demure. Both parenting and society influence and perpetuate the role of gender norms and how they relate to beauty. The experience of gender socialization is universal, though it varies across time, place, and social group memberships, and although it can become problematic, there still is a sense of community when little girls and women from different walks of life are trying to adhere to such a controlling standard. When the ideal standard of beauty is disrupted, whether it be prescribed or ascribed, the disadvantage is that we are not brought up nor influenced to accept all types of beauty in different forms, causing a distortion in how we perceive ourselves. In sum:

sociologists describe “doing gender” as the idea that gender, an ingrained social construct, is performed in everyday interactions; it is not a set of inherent traits, but rather the accountability we hold to others who are monitoring our gender self-presentation (West & Zimmerman, 1987).

### *Disciplinary & Cultural Domain*

As explained by Lopez and Gadsden (2016), the disciplinary domain of intersectionality emphasizes the organization and regulation of people that reflects our social positions regarding systemic oppression. For this research project, it would have been easier to just overgeneralize the experience of female burn survivors, but there is another major factor, race. While reviewing the existing literature, I found little-to-no information specifically on *Black women survivors of burn trauma*. This gap in the literature indicates the need for new research protocols particularly designed to shine light on Black women’s experiences of trauma.

Black women’s traumatic experiences must be analyzed through their specific cultural context. Materials circulated by the Phoenix Society for Burn Survivors state that trauma challenges our sense of safety and security in the world, it prompts us to ask meaningful questions about life and then creates uncertainty about where we fit into the world and our future (Bosch & Rutter, 2020), much like Gay Becker’s work. Typically, those who experience trauma in Black and Brown communities experience compounded oppression compared to the experience of trauma survivors of the dominant culture (Crenshaw cited in Bryant-Davis, 2019). Researchers have indicated that culture is a vital part of vulnerability to, experience of, and recovery from distress (Bryant-Davis, 2019). Trauma survivors from differing ethnic backgrounds are said to hold many identities simultaneously that aid in their understanding of trauma and the healing process that follows.

There is little-to-no platform for burn survivors where their permanently unsettled appearance is represented in an accepting manner; rather, they are forced to create their own notions of beauty. The survivor of a horrific event like a fire can feel like she is forever the “odd ball out,” and can experience that she is silently shunned by society; as an injured woman I believe I can never fully feel desirable; some people express surprise that burn survivors procreate, as if the survivor were some foreign creature and no longer a human being who can enjoy and experience life like everyone else. Until recently, burn survivors in the media were portrayed in monstrous ways (e.g., the *Nightmare on Elm Street* movie franchise wherein Freddy Krueger’s backstory involves being burnt alive by a mob, dying, then striking a deal with dream demons to resurrect as an undead, nightmare-controlling fiend). Now, they are represented often from a place of pity, or their experience is angled for a “feel good story.”

There is an existing literature on this realm of unwarranted media exposure for those considered under the broad umbrella of “disability.” An Australian disability activist named Stella Young coined the term “inspiration porn.” This term had a strong correlation to an older term called “supercrip,” and both concepts have similar foundations in their attempt to create a moment rooted in “inspiration, awe, tragedy, triumph, and pity; they also presume a non-disabled audience and engage ableist concepts” (Schalk, 2018, p. 101). It is important to consider how images and narratives of marginalized people in the media, popular culture, and elsewhere can contribute to hierarchy by perpetuating negative stereotypes; in this case, of burn survivors. The cultural domain of power can help us to understand this dynamic further.

The main difference between *inspiration porn* and *supercrip*, is that the former often embodies the image of abled people “helping” those who are disabled, whereas the latter

painted the narrative of those disabled people as inspiring or extraordinary for doing the simplest activities in life. While the ideology of the older term “supercrip” is still prevalent, inspiration porn is more common in our current social climate because it is used in reference to memes, photos, videos, and news stories that are shared on the internet (Schalk, 2018). Schalk (2018) points out that the scholarly work on both notions framing the perception of disability do not consider race. A further gap in this literature emerges, given that only a few scholars have studied how audience identity impacts the perception and representation of disabled people.

It appears that the focus of disability studies is on the general response by (and to) disabled people on a macro level, yet this narrative appears to overlook disabled people of color. We should consider how to incorporate their perspectives in disability studies. Schalk’s (2018) conclusion to this inequity is that racial differences in the framing of these clickbait, viral moments “provide context into disability studies, like inspiration porn, which have been primarily developed and deployed in regard to white experiences and representations of disability, [which] may need to be adjusted or discarded in the context of racialized subjects to account for the specificity of cultural norms and racial histories” (p. 103). Thus, there is a framing problem in disability studies and researchers must explore the potential need to adjust or discard certain themes, such as *inspiration porn*, when considering racialized subjects. This is due to unequal histories in the U.S. when it comes to race, influencing which groups are looked to for inspiration and which groups are (dis)regarded through limiting controlling images.

For example, Kechi Okwuchi gained notoriety in 2017 *not* for her impeccable singing on *America’s Got Talent*, but rather for her scars as a Black woman burn survivor. The story of her accident and her physical appearance created a narrative of “inspiration porn” whereby her

disfigurement rendered her “disabled” by discrimination, her story offered up to provide emotional satisfaction for a non-disabled audience. She did not create that narrative, the media did. Another example, Ivette Ivens posted a photo breastfeeding her baby to her Instagram account; when the media caught wind of it, the headline read, “burn survivor’s breast-feeding photo captivated thousands of people.” Not giving her name in the headline reduced her to her misfortune and the storyline implied that Black women as burn survivors are doubly “defective” in motherhood; the soft bigotry of fueling shock value around imagery that depicted a Black woman burn survivor as a good mother rather than a racialized disfigured monster. Black women's lives have been shaped by assumptions that they are defective mothers while burn survivors are often declared unfit, as well.

In the online archive for the Phoenix Society for burn survivors, there is an article that highlights the microaggressions that people project onto survivors; in an attempt to make burn survivors feel better, the unburned create barriers around our experience and who we are as people with scars. Most times the harmful message is conveyed through microaggressions, but another avenue is microinsults. Microinsults are defined as “unintentional behaviors or verbal comments that convey rudeness or insensitivity or demean a person’s racial heritage/identity, gender identity, religion, ability, or sexual orientation identity. Despite being outside the level of conscious awareness, these subtle snubs are characterized by an insulting hidden message” (Sue, D.W. & Sue, D, 2016, within Anderson & Pyles 2021, para. 25). Examples of this would be “you’re such an inspiration, how can you do that with your burns? Are you able to have kids with your scars?” These statements insinuate that burn survivors are incapable of living a “normal” life.

The media is a powerful institution, perpetually displaying women as commodities and enforcing unrealistic beauty standards. However, there's a disconnect with women who do not fit into this frame, which constitutes another disadvantage. There is no representation of people who are Black *and* have physical scarring as a love interest in movies or shows; burn survivors do not model in runway shows, catalogs or makeup campaigns. Often when a burn survivor is portrayed in a media outlet, it is in a monstrous way. This is problematic on multiple levels, because historically, women in general have been portrayed in a monstrous way (e.g., in Greek mythology). To add layers to that, Black women have not had the luxury to be considered "just women" who are deserving of humane societal treatment, in all the ways in which white women are, as Sojourner Truth highlights this indifference in her speech/poem "Ain't I A Woman?". In essence, U.S. (white) society has portrayed Black women as scary monsters. To top it all off, burn survivors are the prototype for being monstrous, as we see in films like *Nightmare on Elm Street* and *Girl Interrupted*. Just recently over the summer of 2022, I saw a Dove commercial that had a Black female burn survivor, her skin grafts immediately caught my eye as I wasn't paying much attention to the television, but I suddenly began to cry. I finally saw myself, even if it was for a couple seconds. I was represented as a regular woman who deserves a nice body wash. I felt like I was part of a community and engaged with it, despite critiques of consumerism, or becoming a consumer niche.

### *Structural Connection*

The structural component of intersectionality focuses on institutional arrangements (Lopez & Gadsden 2016). An example of this would be if a survivor's scarring hindered her from obtaining certain economic opportunities. In a study conducted by researchers for the journal



*Burns*, the authors conducted a qualitative study to assess the impairments and barriers for reintegration back into work for burn survivors. The findings were that survivors agreed that return to work efforts were not adequately supported and that education should be provided to work colleagues about the burn and rehabilitation process, but that information on residual impairments should be communicated judiciously as it may be used in a prejudiced manner against those seeking new employment. In the latter case, it is preferable to inform the workplace of their strengths and abilities in efforts to stave off hiring discrimination against burn survivors (Nguyen, et al. 2016). Able-bodiedness and having a job are masculinized; this plays into the politics of respectability. To add another layer, it is no revelation that women are significantly underpaid and underrepresented in the workforce, and to take it a step further, Black women are not awarded the same opportunities as their white counterparts, male or female in its totality. To connect these two, Black women who are burn survivors may be perceived as inadequate or incompetent to employers on multiple levels, and therefore could face the possibility of being paid inadequately or treated unfairly in hiring or the workplace.

### *The Black (Disabled) Woman*

Disability studies have faced challenges in gaining recognition within literature and conversations related to body image, beauty standards, and societal acceptance. Intersectionality is designed to include all the “isms” simultaneously, and historically, disability studies focused on the experience of the disabled person facing barriers to access public services, hardly considering the ways in which gender and race can impact the disabled experience, as well. A Black feminist disability framework can contribute a more complex, in-depth understanding to the Black studies literature and disability rights conversations, stitching them together. To preface this, Black feminist

scholars are trying to debunk the “strong Black woman” narrative that has been pushed on us, and we adopted it. This has become problematic through the years, because this myth “suggests that Black women are uniquely strong, able to endure pain, and surmount otherwise difficult obstacles because of their innate tenacity” (Bailey & Mobley, 2019, p. 21). This statement allows Black women little to no room to be prideful in the ways that they cope with, and function despite, their disability, because the logic of survival and resilience within the Black community has barred weakness and valorized hyper-ability at the same time that Western thought has influenced a negative stereotype of non-normative bodies as the epitome of unsuitability through several domains of life.

Through a historical context, the Black experience is shaped by Black bodies viewed as a productive labor force, leaving little room for an intersectional identity-based approach to race and disability (Bailey & Mobley, 2019, p. 25). The irony of the way that Black people have been perceived by the outside world historically has resulted in our bodies being hyper-able, but our race as fundamentally “crippled.” White supremacy figures Blackness as both hyper-able-bodied and intellectually disabled by race. It can be concluded that ableism and the spectrum of disability are a part of anti-Black rhetoric. It is often stated by disability rights activists that disabled people are the largest minority, in an effort to garner collective action. What it does not do is differentiate the ways in which people become disabled, whether inherent, accidental, or over time. Black Studies AND Disability Studies need to consider that Black women and other women of color are the primary caregivers of disabled people, primarily their disabled family members and others, often doing debilitating work themselves, which can lead to their very own disability. Black and other people of color have higher rates of disability than their white

counterparts. In the event of an unforeseen accident that results in disability, there's a high chance that one would have to miss work or cut down on their labor done to make money. Being that Black women make an overall lower pay than their white counterparts, this can potentially impact how much they receive in benefits either from their jobs or the government.

Bailey and Mobley (2019) conclude that a "Black feminist disability framework would reconceptualize our ideas about work and labor," and it would "ensure that race, age of onset, method of acquirement, gender, sexuality, and other important aspects of the way disability is multiply inflected are brought to bear in our analysis" (p. 32). These authors also suggests that if Black Studies took up disability and gender more comprehensively and productively confronted ableism, we might rid this field of ableist language and create a new, inclusive language. Likewise, if Disability Studies took up Black Studies and Critical Race Theory in ways that displaced the white disabled body as the norm, we might gain a stronger, more relevant framework to critique neoliberal capitalism (Bailey & Mobley, 2019, p. 35).

### *The Looking-Glass Self*

It is appropriate to incorporate the classic theory of the "looking-glass self," a phrase coined by sociologist Charles Horton Cooley (1902). The looking-glass self is the process in which we base our sense of "self" or identity as a reflection of how other people view us. The theory is used as a framework by social and behavioral scientists as well as researchers to analyze how an individual's self-image is imagined by others (Jackson & Hogg, 2010). There are three stages to the looking-glass self as explained by Cooley, with the first being how we imagine ourselves to appear to others, the second being our implications of how others think of us or how we appear, and the last is whether we alter our appearance or behavior based on others' perception. It is

believed to be a part of human interaction to seek validation and approval from others, as it aids in building our self-esteem (or not) and ultimately what comprises our personalities.

This theoretical framing is vital to the topic of body image, especially when there are bodily differences involved. To take it a step further, adding interlocking layers of marginalization also has a unique relationship to the looking-glass-self theory. Dr. Rahim (2010) wrote in his article “Marginalized by the Looking Glass Self” that “stereotypes and labeling can influence how marginalized people see themselves, and how they think they should appear in front of others” (p. 3). People of color who come from urban communities already face scrutiny and labeling from society, and this looking-glass theory’s implications can be even more detrimental to those who are outside of the frame that society tries to put us in, referencing Kimberlè Crenshaw’s idea of a “framing problem.”

While examining the concept of the looking-glass self, it is important to note that we ourselves are imagining the thoughts of others’ perception of us, and this creates a response of self-feelings as mentioned by Downey (2019); these feelings include pride, shame, and envy. Researchers studying the psychosocial effects of people with physical scarring suggest that shame plays an important role and that the experience of social exclusion can lead people with a visible difference in their appearance to develop social anxiety specific to their appearance concern (Pasterfield, Clarke, & Thompson, 2019). Also noteworthy is that negative emotions surrounding one’s disfigurement can vary by the importance we place on those who judge us and the context in which the interaction took place (Downey, 2019). Burn survivors can look for acceptance and validation from people who may or may not be close to them. However,

usually, after a horrific accident that results in physical injury, we seek support and validation through our closest peers to help us heal both internally and externally.

A sense of “normality” is often desired after suffering a life-altering event, so the people in our innermost circles tend to play a vital part in how we see ourselves and continue to navigate life. The outside public acting as a mirror of our reflection is what tends to be the struggle. Before a traumatic accident that alters physical appearance, going out in public and interacting with others could still be potentially nerve wracking for those who suffer from anxiety of some sort; but there’s a likelihood that the fear is within the individual, and people are not staring at them or thinking negatively of them. Without trying to undermine the experience of “normal” people, someone who has physical scarring or disfigurement can often see and/or feel others staring at them, confirming their fears of being negatively judged. This interaction, real or imagined, makes the person with a disfigurement feel like a curiosity in the eyes of others. While people will stare at what they may often not even see, the object of their gaze, the survivor, can be left with imagining and projecting onto others what they may be thinking about us, but without context of what the bystander “really” thinks. Cooley does mention that there is a certain amount of agency an individual possesses that helps cultivate such self-denigrating thoughts and perceptions we may imagine others to have of us. In this case, already having convinced ourselves that we are “not normal,” we project our own perception of ourselves onto others.

Anthropological views of the self are often analyzed, as well, and the debates are typically centered on what is more influential on the “self” and how much of the self is culturally determined. There are two perspectives that are at the forefront of this debate in the social sciences: a “normative” perspective and an “alternate” view that suggests that the notion

of a cohesive self is illusory (Murray as cited in Becker, 1997). Murray originally characterized these two perspectives as transcendent and contingent. The “normative” or transcendent self is viewed as cohesive, bounded, autonomous, continuous, and stable. This version of the self is the most traditional in Western culture, which values autonomy and independence, and leans the furthest into the social structure and individual agency. To the contrary, the “alternate” or contingent self is often linked to cross-cultural work, and emphasizes contested and negotiated meanings, diversity, and inner experience. Scholars suggest that individuals with this perception of self continuously reconstitute their identities in response to the internal and external stimuli as a “string of selves” which is everchanging, in which a person may overlook inconsistencies and experience wholeness and continuity (Becker, 1997, p. 387). The Black female burn survivor will more than likely perceive the self in a “contingent” way based on this analysis, because she must redefine and adopt new views of the self and continue through life with a new identity.

Being a survivor of any sort of accident is no easy task or journey to embark on. Most people have gone through some level of trauma, whether emotionally/mentally or physically, and usually both. There’s a unique complexity to dealing with both emotional/mental and physical scarring as a burn survivor; and having physical scars to remind you of a horrific experience is unbearable for most. Responses to trauma can vary at the intersection of gender and race. We must examine more positive outlets to process a traumatic experience that leaves us physically scarred and disfigured; we must also learn to create our own notions of beauty to overcome rejection, whether real or imagined; most important, however, is to contribute to creating a world with wider definitions of beauty that accepts us as we are, scars and all.

## CHAPTER III: METHODS AND PROCEDURES

### *Design and Methods*

To better understand this phenomenon, I conducted life history interviews with five Black women who are burn survivors. I felt that this approach was the most sustainable as it provides an insight into the lived experience of Black women who are burn survivors before and after their accident/incident, and how they navigate and shape their identities and live their lives. Only one-on-one conversations could help me compose the story I wished to present and analyze.

### *Data Collection*

The sampling technique I used was purposive or quota sampling because I sought a particular demographic of Black women who are burn survivors. I contacted these women via social media, specifically Instagram. I directly messaged them, told them about the study and asked if they would want to be part of it. For my sample size, I hoped to have a maximum of seven, but no less than five, women. I justified this sample size because I wished to have a solid foundation of different accounts of Black women's experiences. At the same time, I preferred to avoid any redundancy or similar emerging themes as I talked to these women; therefore, I felt comfortable that my sample did not exceed five subjects. I chose Black female survivors as a sample because I expected that the ways in which Black women respond to trauma that leaves them physically scarred would present with significantly different responses to their trauma compared to the responses of other race-gender demographics.

### *Ethical Issues: Informed Consent*

As mentioned above, I reached out to women explaining the purpose of my study. I thought it was important to lead with the fact that I too am a survivor, and hopefully that brought some level of comfort to women I interviewed. To avoid any type of harm to my subjects, I disclosed in my letter of consent that if at any time they felt uncomfortable or overwhelmed by the questions in any way, they were free to stop at any time, whether it was temporarily to collect themselves or to altogether discontinue participating. I personally felt no harm inflicted on me as this interview style was heavily conversation oriented; I just tried to get a further insider's perspective. The participants were free to choose whether to remain anonymous or not. They also signed an agreement that my records and the data that I have collected will be kept secure through devices (phone, laptop, iPad) that will have a unique password just for the interview recordings and transcripts. I did not offer any material object or item of remuneration to my participants.

### *Ethical Implications/Limitations*

Potential issues I thought I might face in this study included the following:

- 1) Refusal to participate
- 2) The interview questions could potentially be triggering and bringing up suppressed emotions, which would be categorized as "harmful" to the participant.
- 3) Accurate recollection of the incident, subjects' willingness to be completely open and honest about their experience, and in turn, my trusting that what they say to me is true.
- 4) My sample of five participants cannot represent a whole demographic.



### *Reflexivity*

As mentioned periodically throughout this thesis, I have a close relationship to this research topic as I identify as a burn survivor and as a Black woman. Over the years, I yearned to talk to somebody who experienced the same level of physical and mental traumas as I did. I believe this connection, and ultimately seeing me as a reflection of themselves helped my participants feel comfortable confiding in me. I do not believe there is anything different about me that made the participants reticent to speak with me. The interview questions are questions that I have asked myself over the years, as well as questions that others have posed to me that I had difficulty answering after my accident.

### *Data Management and Analysis Procedures*

All interviews were held via Zoom, and I recorded the conversation to access later, as well as to use the Zoom transcription feature to transcribe the interviews, then code them. I personally did not have any pre-established codes and rather coded my data, remaining open to the themes that emerged. The choice behind this is the desire to pick out emerging themes from what the participants said instead of going in with pre-conceived expectations/codes and being disappointed if their responses did not “fit.” In the Findings chapter that follows, I selected emerging themes and considered where they fit into my research questions, sensitized to the literature that I read for the front matter of my thesis.

## CHAPTER IV: FINDINGS

I had the pleasure of speaking to five Black women burn survivors in order to better illustrate the purpose of this study. The participants included: *Markeyla Williams* (Alabama, age 26), *Taylor Charles* (Texas, age 26), *Julie Sanders* (Florida, age 29), *Afia Fields* (Maryland, age 32), and *Karli Butler* (Illinois, age 40). All participants in the study are single, and two of them are mothers.

Most of the burn incidents that occurred were described as “freak” accidents. However, one incident was a pre-meditated attack. I will be incorporating details from that story into my findings through the responses of the individual in question. These women generously shared their experiences, and how it affected their lives and sense of self during their healing process and afterwards.

Each interview covered four main topics: 1) demographics, 2) perspectives on disability/injury/impairment, 3) emotional/psychological effects, and 4) interpretations of beauty standards. For a full listing of questions, see the interview guide in the Appendix. The following presents data from shared themes across interviews, making note of differing perspectives and responses.

### *Survivor or Victim?*

Being that I am an insider to this research as it is my personal life experience, I navigated my life labeling myself as a burn “survivor,” as I felt the term “victim” had a negative and or defeatist connotation to it. While pitching this idea to other scholars, they revealed to me that the term “survivor” should not be assumed to be true for every other person who has gone

through a traumatic event. I was encouraged to extend my participants the agency to inform me of how *they* identify themselves after their burn incidents.

Thus, wanting to gauge how the respondents identify, I led up to, and asked in the interviews, “I’m learning that terminology is important... because as Black women, we are *expected* to be strong and resilient through anything life throws at us. So, how do *you* label yourself after being burned?”. After interviewing multiple respondents, I identified that all of them “definitely” refer to themselves as “survivors” rather than “victims.” One respondent was told by a therapist to stop using the term “victim” and to use “survivor,” instead. Many of the respondents noted that it took time to adopt a survivor mindset, and to change their mentality from victim to survivor. One person explained that they sought to regain power that the burn incident had taken away from them. Another respondent stated that survivor refers to someone who can overcome obstacles and adapt to a “new normal” to carry on with her life. In the words of the respondents:

**Taylor:** Survivor! (No further explanation)

**Markeyla:** My accident was one of those things they call a “freak accident”-type thing, and with the circumstances of it all, I wasn’t supposed to survive that, know what I mean? So, I definitely feel like I’m a survivor. It’s a lot to overcome, that people don’t understand, from the background of it all. So, I would call that survival, for sure.

**Julie:** Ooh, I like that question! I refer to myself as a burn “survivor.” When I first got burned, I got into a therapy group for burn survivors, and [she] would always press like, “don’t call yourself a victim.” So yeah, definitely burn survivor.

**Karli:** Oh yeah, I’m definitely a survivor. It’s like yeah, something happened to me that made me a victim, but I took my power back, and that’s what made me a survivor.

**Afia:** I call myself a survivor. I think of it as how you live your life after the incident that makes you a survivor.

These responses all have similarities in illustrating the theme of Black women's resilience after burn incidents, and overcoming what most would consider impossible, as emphasized by Markeyla, Karli, and Afia. Making it out alive and continuing life is *survival* according to these responses. Julie's response emphasizes the importance of reframing one's mindset and that there is power in words and labels, and how one simply chooses to identify herself has a strong connection to how she lives her life after a traumatic, life-altering event. Julie and Karlie discussed in a roundabout way the challenges associated with the strong-Black-woman archetype, particularly the balancing act of walking a tightrope from vulnerability to strength.

#### *The Circumstances Leading to and after the Burn Incident*

A classic sociological perspective tells us that biography and history shape our life experiences (see C. Wright Mills, 1959, *The Sociological Imagination*). As this framework relates to the relevance of the study, I believe that the time (age, lifecourse stage) and place (environment, context of a major incident) plays a vital role in how each of these women understood their identities and lived their lives after being burned. Likewise, we as individuals in this society/culture have an idea or expectation of where we should be developmentally at certain stages of our life. When a traumatic event suddenly disrupts our lives, it alters our perception of the self and the *quality* of our lives as we once knew it, as explained by Gay Becker in "Metaphors in Disrupted Lives" (1997). All these women have different stories that placed them at different points in their lives at the time of their incidents. After they told me the detailed story of the events that led to their accidents, I was intrigued to know more about their account of how the incident disrupted their lives at that moment and changed the trajectory of where they thought they were going. Three women were college students, one

was a new mother, and one was a toddler when the burn incident occurred. To give more context, I included a brief description of how they all became burn survivors.

**Taylor** (burned in a car explosion in 2016): I never went back to school after I recovered. I'm actually still debating if I wanna go back to school. I probably should .....I never went back to work for anybody. My mom does decorations, so I help her with that, but I never went out and worked for another company or anything like that.

**I:** So, you never "went back" to anything you were once part of in your life prior to your incident? In a way, you started a new life.

**Taylor:** Basically, now I'm thinking of ways to start my own business. I'm kinda happy in that way, because I'm not sure if anybody would understand my injuries .....I feel like that will make it hard trying to find a job. It's best for me to start my own business or continue helping my mom with hers.

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**Julie** (burned from grease spill in 2016): I'm a busybody. I like to be busy doing a lot of things. So, at the time I was in school, and it was summer vacation. I was out of the hospital before the semester started, so it didn't really disrupt my school situation. But, at the time I was a bartender, doing hair, and making treats, which requires standing. When I got out of the hospital, I couldn't stand for five seconds straight... so I'm like yeah this is not happening anymore.

**Markeyla** (accidentally lit herself on fire after doing her hair): I had my son. My son was one at the time. I had my grandmother. She was there at the time and put her life on hold to take care of my baby, and you know... made sure I could see my baby every weekend in the hospital. ... My son missed out on how to be a kid, because he saw his mom needed to be taken care of. He grew older thinking he HAD to take care of me. My brother was 8 or 9 at the time. I felt bad because I felt like I took my mom away from him at that time because I became the baby.

**Karli** (viciously attacked twice in pre-meditated act of crime, dowsed in acid): All my roles were stripped of me. My mom had just passed the year prior, and I feel like I failed (my dad) as a daughter and sister because I had to stop grad school. My role as a girlfriend was taken, I had to cut him off, and I couldn't party or travel.

**Afia** (burned in house fire): I was three when my accident happened. The doctors told my mom not to send me to public school. I remember wanting to tell all the other kids what happened to me I remember having to relearn (eating, walking, potty training) what I had JUST learned.

The burn incident had significant physical, interpersonal, and structural-level consequences for the Black women I interviewed, impacting their family, school, job, and community security. Many of them had to discontinue their studies or stop working altogether, either due to physical limitations or fear of discrimination based on their appearance. Some experienced disruption to their family dynamics, while others felt a dramatic change in their sense of identity. They faced the challenge of relearning everyday tasks such as eating and walking. However, one respondent saw a “bright side,” as she was now free to pursue the possibility of starting her own business from home, given the feeling of being homebound.

### *Inequitable Medical Experiences*

There is ample literature that focuses on the injustices that women of color face in the medical field regarding adequate treatment. While most documented injustices surround the mortality rate of Black mothers during childbirth, there is general prejudice toward Black women in the healthcare field. These prejudices can be in the form of stereotyping, labeling, obliviousness, and negligence. People of color are also limited in their access and resources concerning certain cosmetic procedures due to there not being adequate technology to help or conceal affected areas for potential fear of further damaging melanated skin.

Unfortunately, history reveals that the medical field has not been so kind and understanding to people of color, as explained by Hawley and Flint (2016): “People perceive Blacks as feeling less pain than whites” (p. 31); therefore, caregivers are less attentive to Black people’s pain and suffering. I asked my participants to recount their medical experiences.

**Markeyla:** I would rate my hospital experience an 8 out of 10. My total recovery time was about two-and-a-half years. I literally lived there; thank God I had a good experience. I will

say Black people do scar differently than white people do. I saw Caucasian burn survivors when I was in the hospital, and their scars didn't look like mine. They don't really keloid [scar] like we do either, which is why they may get better options for treatment and stuff like that.

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**Julie:** When I got to the first hospital, they... downplayed what happened. They were like "oh those are just 1<sup>st</sup> and 2<sup>nd</sup> degree burns." First red flag in the situation because they were *absolutely not* 1<sup>st</sup> and 2<sup>nd</sup> degree burns. They told me they couldn't do anything to manage my pain, so they shipped me to another hospital.... The second hospital was a disaster!

**I:** Oh no! What happened?

**Julie:** I was there for probably a month. They would've kept me longer, but I was like "Listen, I gotta go, I gotta get out of here." I remember one day, some of the nurses tried to flip me over to change the... pad on the bed. I was like "I'm in a lot of pain, I can't do this." At first, they said they weren't gonna force me. Then, they called this guy in to help them, and this man literally flipped me and said, "You're being dramatic." ...I don't know if this was bias towards Black people, but before I was even discharged, they took me off the pain medication. I'm like "I'm not NEARLY done healing!" ...I would not recommend that hospital at all.

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**Karlie:** Overall I would say I had a positive experience. I had good insurance, and I was treated at one of the best burn units in the country, the University of Chicago. I will say the medications were hard, and I had no idea how long the recovery process would take I just wanted to feel better, so I signed on to take methadone. It's one of the most powerful drugs. I could've got addicted.

**I:** How did you get off it?

**Karli:** I tried to quit cold turkey. Due to that, doctors labeled me "problematic" and "medication seeking" on my charts, without knowing the full story.

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**Afia:** I've had a lot of surgeries throughout the years. I stopped getting procedures after a while, then I started back in 2019. I had a good relationship and really trusted my doctor.... But when he retired, I struggled finding a doctor who supports me and is familiar with my story and body. I miss that relationship.

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**Taylor:** I do think I see [on social media] like more white people, and other [races of] people get more resources for their burns than Black people do. I think I see that more often.

I: I remember sometime after my incident, I was seeking some cosmetic correction for the scar on my lip, and many doctors turned me down because they didn't have the right laser equipment to treat Black skin.

**Taylor:** Thank you so much for reminding me! ...So, I'm on social media, and I remember there was this white girl who was a burn survivor, and she's showing the before and after of her laser procedure, and I'm like oh my God, I think I wanna try this. So, I mention it to my doctor, and he's like "well, it can result in keloids, or make your skin way darker." I was lighter than this prior to my accident, so I didn't wanna risk that... I did get *some* laser and it kinda smoothed it out, but I knew it would be way better if I had lighter skin ...I guess that is the reality if you're a Black person wanting laser; it's easier to do it with lighter skin tones That did make me kinda sad, because I saw other people on social media that had laser and it helped them so much.

My interviews with Black women burn survivors revealed a concerning trend regarding their healthcare experiences. Many reported that medical professionals were dismissive of their pain and micro-aggressed them, as well as stereotyping them as being overly dramatic. Additionally, they were often prescribed pain medication, which was stopped abruptly, with no help in tapering the dosage. Those who questioned this treatment were labeled as having drug-seeking behavior. Furthermore, they found it difficult to find doctors who were knowledgeable in treating Black women's skin. Finally, while social media advertises laser treatment resources, these tend to be more effective on lighter skin tones and can lead to discoloration on darker skin.

### *Disability's Role in Life after being Burned*

A vital part of using the intersectionality framework is incorporating the world of disability studies. Stevens-Watkins et al. (2014) suggests that the only way to accurately examine body image and beauty among African American women is through intersectionality,



which is the interlocking of all the “isms.” As disability and its correlate ableism is included in all these “isms,” there is a unique perspective that often gets overlooked, that being a Black feminist disability framework (Bailey & Mobley, 2019). Bailey and Mobley (2019) argue that historically, disability has been studied from a white person’s perspective, and that has become problematic due to there being the compounding effect of race establishing hierarchies of difference that contributes to the disabled person’s experience.

Aside from having physical scarring, the degree of the burn injury can result in life-altering debilitations, such as loss of limbs, eyesight, and bodily mobility. As a result of this sudden major bodily change, the world of these women changed in various ways, affecting their work life, social life, and daily independence.

**Karli:** I often ask, “What is disability? What does it really mean?”

**I:** So, you feel it’s subjective?

**Karli:** Exactly. Scars are a curse, I literally have to wear my past on my face, that is a disability within itself. My eye wouldn’t close for months and being that most of my injury was on my face from the acid, I had to wear a face mask during recovery, I would literally scare people.... I thought I would be “disabled” forever. That was then though, I currently don’t have any mental or physical disabilities.

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**Afia:** Bree, can you hold your hands up please?

**I:** \*holds hands up\*

**Afia:** now bend your fingers down at the knuckle. That’s my disability, on both hands. Yes, I have had a disability since I was three years old. I really don’t know a life without it. I’m very independent.

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**Taylor:** I was really independent before my accident, but now my vision is not the best..... I actually lost my eyesight after my accident, for about four months. I have optic nerve damage in both of my eyes, so I can’t drive anymore. On my left hand, the tips of my fingers

got cut off. I was left-handed, so I had to learn how to use my right hand .... [plus] having to deal with the insecurity of not being able to see good, like if I'm with people and we're watching something and they're like "oh did you see that?", and also the insecurity with my hand. Those are my disabilities.

**Julie:** I only felt disabled in the beginning. My injuries are on my back and legs, so when I got out of the hospital, they wanted me to use a walker, and there was a lot of physical therapy to get my range of motion back but I haven't thought about it or felt "that way" in a long time.

**Markeyla:** When I had my first couple of surgeries, they had to use pig skin and layer it, because I was burned so bad. And even now, my scars have a keloid effect, very bulky. My right hand was one of the scars I had the worst. I had to have three surgeries just on this hand. The skin began to keloid and became so thick, that it started to connect, so I can't stretch my right hand all the way open It affects my job because I do work from home, and it's not as easy typing.

These interview excerpts indicate that some of the respondents experienced short-term disabilities. For instance, one person needed a walker to aid in rehabilitation, while one respondent endured a chemical burn and had to wear a burn face mask. Considering the latter, I would like to highlight Talley's (2014) research on disfigurement and the stigma around it, which is relevant to my study. According to her work on *Saving Face: Disfigurement and the Politics of Appearance*, privilege and inequality are associated with facial appearance, and we must not neglect the cultural background of something like a latex monster mask when critically analyzing how we perceive the human face, or lack thereof, as "scary." Moreover, Talley's (2014) studies volunteering at a camp for children with severe burns indicate that recovery efforts focused on burn repair may actually *amplify* the stigma around disfigurement.

Other respondents suffered long-term disability following burn injuries. These individuals experienced difficulties such as the inability to bend burn-damaged fingers, low vision, fingertip

injury or amputation, and other anatomical injuries. One respondent even mentioned that the thickness of the pigskin grafts on her various hand scars merged, making her hand heavy and tight. This has made it difficult for her to perform her typing job, which highlights the importance of being mindful of such circumstances and their consequences for one's economic livelihood.

Likewise, another part of the complications of disability could be receiving benefits. There are many requirements that must be met to qualify for state assistance from the government, and a couple of the participants shared their struggles with obtaining disability benefits. Bailey & Mobley (2019) emphasize this notion, indicating that “Black workers in every age group shown are more likely to die or become eligible for Social Security disability benefits [but] ...because social security benefits are often based on previous wage labor, Black people—and Black women specifically—drawing social security are drawing from a lower overall rate of pay from their white predecessors, thus impacting how much support they are eligible for” (pp. 32–33). Two of my participants recounted their experience with this specific issue:

**Markeyla:** Well for one, it took a long time for me to get disability and all that stuff, which is like a whole other world. You know you hear about disability and social security and all that, and when you're younger you think it's only for older people. But when you're younger, it's a complete rip-off! They don't give you enough, and for one I didn't work long enough. I was young! I wasn't working for years and years and years to be getting a lot of money, so I had to wait on that. I had to try to make money at home, like really hustle.

**Karli:** I had a quarter million-dollar hospital bill. Every program I applied to kept denying me, saying I didn't qualify.... It added so much stress onto my recovery. I didn't know how I was going to take care of myself.

In these interview excerpts, we see concerning findings from my research regarding early adulthood and disability at the race-gender nexus. Specifically, I found that my interviewees as

relatively young individuals with early onset disabilities faced modest benefits that are insufficient for living. Furthermore, our capitalist society often exacerbates these issues through gender-and-racial income and wealth discrepancies, especially when it comes to unexpected and uninsured medical costs for Black women. I found that this financial stressor adds to the already stressful recovery process for burn survivors. The respondents I interviewed also expressed feeling abandoned by society and left to fend for themselves. This sentiment aligns with Crenshaw's idea of Black women being neglected by our society.

#### *Social Re-integration / Navigating Womanhood as a Burn Survivor*

The participants were asked to share their experiences of re-integration into society after their burn incident and navigating Black womanhood through the lens of gender differences, and the limitations that they face in their social and personal lives. The interviewees' responses prompted connections to themes in prior research I had been sensitized too, drawing from two parts of the literature: intersectionality focusing on race and gender; and the looking-glass self. Altered appearances due to burns can cause stress for the survivor complicated by gender, and studies have shown that female burn survivors report greater body-image dissatisfaction than male burn survivors (Levi et al., 2018). To provide a full and accurate representation of the respondents' tone and consciousness throughout this portion of the interview, I found it necessary to include lengthy quotes from the transcript. I believe this effectively communicates the nuances of their responses.

**Julie:** I was 22, I was in college, I was physically fit, I was outside you know? After my accident, I guess it made me no longer want to be out, or wanna go be social. If I couldn't find an outfit that covered my legs, I wasn't going.... I feel like it made me a homebody.

**I:** How did the people around you treat you?

**Julie:** In my friend groups or my friend settings, it'd be awkward. For some reason, my accident became very public.....I remember going to a baby shower a few months after, and everyone is looking at you a certain way .... It was like a pity or something, definitely not a good feeling.

**I:** Do you feel like that translates over into your life *now*?

**Julie:** Even now I feel like I've lost so many "social friends" because I was always turning down their invitations.

**I:** Have you had any issues with dating?

**Julie:** Honestly, I haven't had any issues with dating concerning my scars. If anything, if a "popular" guy likes me, it's *other women* that are catty. They're always like "really, a burn survivor, you don't see her scars?". That was my experience.

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**Taylor:** I do think it's harder getting back into the world being a burn survivor woman, in a way, because we HAVE to be beautiful. Especially when you're trying to date, or even trying to find a job, because you know, how looks [matter] I do think dating is a challenge. It could be more in my head maybe... because it's hard finding somebody that's interested in me.... Or maybe they are interested in me, but it's like do you *really* see yourself being with me, for like the long haul?

**I:** Do you ever self-sabotage? Like internalizing what [they] may think of you without giving them a fair chance?

**Taylor:** It could be more so, me being in my head. I feel like the majority of the people that come to me are like "yeah, you're a cool person to hang with," ...and they probably do think I'm beautiful but at the end of the day I don't think it'll be anything long term because you are gonna have to deal with my insecurities about being a burn survivor, and my disabilities as well Also, ever since my accident, I'm not sure if I'm gonna be able to have children.

**I:** Do you experience social anxiety in any way?

**Taylor:** Sometimes I do have the gather the courage to go out in public because you don't want to be stared at you know? ...Or even if you're not being stared at, you THINK you're being stared at It was tough because at the time I had two close friends, and they just couldn't deal, them seeing me in that way when I got out of hospital put a strain on our relationship.... It made me wonder like "is a friend gonna invite me out, will they wanna be around me in public?".

**Markeyla:** It seems like men do get to wear their scars as a badge of honor, walking around like it doesn't affect them. Whereas us, when anything changes with our bodies, we instantly feel like something is wrong with us. I feel like a lot of that has to do with society and social media as well. I remember I was just starting to accept my new "mom body" because I had a C-section with my son, then I got burned and had to accept these scars as well.

**I:** Would you mind sharing your dating experience?

**Markeyla:** I felt like I cared too much about what a man would think of me and my scars. I had to stop that. Even sometimes now on dates, when we go out in public I'm thinking "you don't feel no type of way that people are staring?" It took me awhile to get out of only showing them a few pictures [on dating sites], or we get on facetime and I'm only showing my face and not my body, ...feeling uncomfortable within myself.

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**Karli:** My story is very public. Like everyone heard what happened to me. You can literally google me, ...and I felt like sometimes my notoriety scared people away. I found myself having to explain a lot [socially and professionally]. When I'm out in public, of course I get the stares and everything, but I don't think it's blatant, but more so internalized....

**I:** Do you think there's a difference in the ways in which gender plays a role in re-integration back into society?

**Karli:** Oh, definitely. No matter what a woman goes through, we're expected to snap back immediately and get it together, like physically and mentally. I think my story is a prime example of *gender-based* violence, being that I was a "conventionally attractive" woman prior to my attack. [My attacker] thought the best way to ruin my life is to ruin my looks.

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**Afia:** Well, being that I'm an actress, I face rejection daily. I think men are deemed "heroic" for their scars. I remember once, I met male a burn survivor, and just in casual conversation I learned that he had been given the same opportunities in Hollywood that I got rejected for. ...I've been a burn survivor for 30 years, Bree. This is the only life I know. I expect all eyes to be on me. Honestly, I don't really experience social anxiety. I have no other "appearance" to compare myself to. I can't hide my scars, so I just live my life.

A reoccurring theme in these responses was the internalized battle within the self of how the respondents imagined themselves, and how they THOUGHT others perceived them. Rahim

(2010) indicates that the looking-glass-self theory can speak to multilayered marginalizations in the sense that “stereotypes and labeling can influence how marginalized people see themselves, and how they think they should appear in front of others” (p. 3). Though, as one woman indicated, since her burns occurred as a child, this is the only identity she has ever known.

The respondents went through bouts of feeling unadventurous, especially if they struggled to conceal their burn scars. Others faced being treated as pitiable creatures once their incident went public. Most of these women struggled to imagine men who could date a physically and emotionally scarred woman. The women reported overanalyzing and overthinking dating, worried potential partners could not handle going out with a burned woman for the long haul. They question whether potential partners would be willing to be seen with a scarred woman who has insecurities and disabilities, or because of her accident, unable to fulfill the reproductive imperative put upon women. Most had to muster up the courage to go into public, always on the lookout for stares. They worried people did not invite them out for fear of “courtesy stigma” (Goffman 1963).

For men, the women understood that scars can be a badge of honor, with men’s scars making one distinguished in Hollywood or entertainment. Or one respondent understood that a “dad bod” is considered attractive, but that she had dealt with the gender-based double standards that her “mom bod” was shameful, now further complicated by her burn scars. One woman’s notoriety of having burns from acid dousing she thought scared off potential suitors. This was an act of gender-based violence, given her attacker(s) knew that one way to ruin a woman is to destroy her appearance.

### *Coping Strategies for Black Women Burn Survivors*

Black people are far less likely to seek mental-health treatment than whites, but especially after a traumatic event. In U.S. history and within Black culture, women were and are held to high standards of resilience that has transcended through generations, some placed upon us through controlling images of mammies and matriarchs (Collins 2022), and others we assumed ourselves through a life of hardship and struggle. As explained in the literature pertaining to Black women and how we cope with mental-health struggles: Black “women tend to report avoidant and passive coping strategies which place them at an increased risk for lower psychological adjustment” (Stevens-Watkins et al., 2014, p. 328). I asked my participants if they were given the space and opportunity by friends and family to be vulnerable in their healing and recovery, and if they felt the societal or familial pressure to be the “strong Black woman.” Likewise, I asked about their mental health journey and if they sought professional help. Their narrative responses to these paired questions were particularly telling and are quoted at length.

**Markeyla:** I feel like the mental health of it all, I’m still working on it I haven’t... built up the courage to speak to someone, but I feel like... most of my therapy comes from God in a weird way. My son’s father passed right before my accident. I put THAT grief behind me because I was like “I gotta focus on getting well you know.” I had to do a lot of soul searching, a lot of being alone, a lot of hibernation.

I: Do you feel like the strong-Black-woman narrative hindered your healing at all?

**Markeyla:** I feel like it did and didn’t in a certain way because I was telling MYSELF I had to be that... you know? No one forced it on me. But, when I was ready to be vulnerable, I had open arms around me to do so.

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**Taylor:** I actually had a psychiatrist and stayed in communication with him every once in a while. I deal with PTSD and depression.... As far as my support system, I can always go to my mom or best friends when I’m feeling depressed, and they’ll give me words of



encouragement .... But you know, sometimes when you get in the back of your mind, you're like "Oh, well they're probably just telling me this because you know they love me." ... So I think it's helpful in that way to see someone professionally.

**I:** Do you feel like you have to "put on a face" for the sake of the people around you, even when you aren't feeling your best?

**Taylor:** My family and friends always tell me how strong I am, so I believe it. ... I know I'm strong. I weigh my options on when I should go to them for something, like when I should tell them I'm going through this, or I shouldn't... because if I tell them how I'm really feeling, they wouldn't see me as that strong person [they] were saying that I am, which is okay, but then you're gonna start worrying about me. I would say it's more so with my friends than with my family.

**I:** How so?

**Taylor:** Not saying they don't go through stuff, but it's more obvious what I'm going through compared to them. I just feel like I can't go to them, they put that "strong" label on me, assuming that I can handle it.

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**Julie:** I wasn't given space.

**I:** Is that a *them*-thing or a *you*-thing?

**Julie:** Both. On top of being Black, I'm Caribbean, ...and it's not a culture that "coddles" people. Even if I wanted to be babied or you know, take my time to recover, I don't think I would have had the environment to do that in. I don't think anyone would have babied me throughout the situation, I just don't see it.

**I:** So, it never got past, "Are you, okay?" because they assumed you would say "I'm fine."

**Julie:** Exactly. You didn't have the space to be like, "I'm not okay." ...I was a part of a burn support group for a while, and it was godsent.

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**Karli:** I remember my first time seeing myself in the mirror at the hospital. My head was so swollen. I was unrecognizable. I remember just thinking "that's me." I felt numb and lost all motivation. I found myself replaying the incident in my head all the time, I was held at gunpoint before she threw the acid on me. I would say the craziest things like "I should've let her shoot me, [maybe I could've survived it] and maybe she wouldn't have thrown the acid on me I

spiraled to a dark place. I just wanted my mom. I emerged as “survival Karli” and not emotionally well Karli.

**I:** Did you seek professional help?

**Karli:** Yes, I was already in therapy due to my mom recently passing before it happened; after, I had a therapist and a social worker. It honestly saved my life, and reframed my way of thinking. I had room to discuss what I was experiencing. I never felt alone.

**I:** Did you ever feel the obligation to be strong?

**Karli:** Oh yeah, I definitely fell into that strong-Black-woman trope. Now my motto is “get somebody else to do it.” The ways in which I try to go against it are setting boundaries and practicing gratitude.

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**Afia:** I never sought a mental-health professional. I’m more spiritual. I’m just now in recent years tapping into debunking the whole “strong Black woman” mentality. My friends and family have always supported me. I feel like I’m more comfortable putting my pride to the side if it gets hard.

I also thought it was important to ask all participants how they personally cope with their mental-health struggles and basic day-to-day functions when they are potentially not feeling their best. The general theme was typical self-care activities (getting out, consuming their favorite media, being with family and friends, positive words of affirmation), but I particularly found it interesting that all of them said they usually pray, talk to God, or tap into their spirituality. Religion and spirituality have historically and culturally been a primary way in which Black people “deal” with life struggles, dating all the way back to U.S. slavery. Culture shapes the way in which we perceive vulnerability (Bryant-Davis, 2019). Being that we were never *given* the option of resources for mental health, as a result, seeking professional help has been heavily stigmatized in Black culture and rather the respondents often turned to religion and/or spirituality.

All in all, the interviewees shared valuable insights into coping strategies for burn survivors. It came to my attention that many of the survivors had different approaches to seeking professional help and addressing their challenges. Some interviewees disclosed that seeking therapy was a daunting task that required much courage. They relied on self-therapy activities, such as soul-searching, expressing gratitude, and seeking solitude. Others looked to their faith/religion to give them hope during difficult times. A counselor, for some, represented a crucial second opinion that offered a different perspective from family and friends who may be overly sympathetic. For others, a support group specifically for burn survivors or social worker/counselor was a godsend. One survivor's journey to healing included the practice of setting clear boundaries, which was helpful in gaining control over her situation. She discovered that it was essential to put aside her pride and seek assistance for her well-being. Overall, the interviewees' experiences demonstrate a range of coping mechanisms that can be useful in supporting burn survivors in their recovery journey.

Nevertheless, there seems to be an assumption that these women can handle any situation, often attributed to the "strong Black woman" stereotype. It is important to debunk the validity of this assumption. I think this issue is particularly concerning because many of the women interviewed in this study felt they could not show vulnerability or seek help when they needed it. One respondent felt her family's cultural sensibility left little room for "coddling" her in her time of need. Still others, though that they must remain strong so friends and family would not worry. Additionally, it is important to recognize the effects that PTSD can have on someone who has gone through a traumatic experience like a burn injury. We should be aware that living in survival mode is not the same as being emotionally well.

## *Black Women Burn Survivors' Takes on Beauty*

A key piece of this research is placing Black women with physical scarring at the center of many interlocking intersections, and part of that is focusing on the beauty standards within both Eurocentric, or Western traditions of beauty, and *within community* beauty standards, or Afrocentrism. To put the within-beauty standards into perspective, I wanted to ask my participants their definition of beauty, if they felt represented in racial knowledge-based projects such as Black Girl Magic aimed to shine a light on the beauty (literally and figuratively) of Black women, and if they see any implications in the motive of this branding being inclusive of ALL Black women, as well as any interplay with pressures to adhere to dominant (white) beauty standards. Janelle Hobson described the Black-Girl-Magic movement as rooted in the *politics of respectability*; an essentialist tool used historically to combat “white supremacist views of the Black body” (Ford cited in Hobson, 2016, p. 4). A couple participants held a positive perspective of the movement, while others felt they were not represented by it. Here is what they had to say on the matter . . .

**Markeyla:** My definition of beauty is who you are within. It has nothing to do with the outer you.... I see myself in Black Girl Magic, because to be honest, we are the blueprints, the originals, we are what *they* want to be. I would even say all the cosmetic procedures as of lately that are dominating the European market are influenced by Black women ....As Black women we're all the same. We all deal with some similarity at one point or another when it comes to image and things like that.

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**Karli:** Beauty to me is how you show up in the world. It's internal, centered around your attitude, and kindness. Before my accident, I attributed my beauty to my looks.... After, it's more about my resilience, and my will to keep getting better and to keep living.

**I:** How do you feel about Black Girl Magic?

**Karli:** I believe that anything that celebrates the individuality of Black women is a win. I feel like it's more accomplish[ment]-based than anything else. I think it's for anyone and is inclusive ....I've had both positive and negative experiences with Black women. I'll say that I have been oppressed by other Black women. I'm light-skinned in a family that's mostly dark-skinned, so I've heard all the "you're not Black enough" stuff.

**I:** How do you feel race plays into this?

**Karli:** I think as Black women, we have been tricked over time to equate our value to one's proximity to whiteness. We navigate our lives and center our goals in relation to how "palatable" we are to white people; I think it has a lot to do with the politics of respectability. Being that I carry myself a certain way, in professional settings they thought I was one of them.

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*When I first asked Afia this question about Black Girl Magic, she was silent and opted to skip. After explaining further what I meant and my opinion, she felt compelled to share her thoughts.*

**Afia:** I feel like beauty is rare... that's it. Black Girl Magic isn't what it was years ago. I feel more undercut jealously from other Black women more than anything because I have confidence.... It's like they want me to pity myself and be miserable. For example, although I have scars, I have a nice-shaped body and like to flaunt it. Black women always say, "How are you so confident?" Even in altercations, they feel like they can get to me by throwing my scars in my face, this even happened with *another* burn survivor.

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**Julie:** I feel like it's so cliché to say, but beauty is within. I grew up with a friend that had a huge birthmark on her face, so I feel like I always grew up still being able to see the beauty in someone, even if they're different.... As far as Black Girl Magic, I don't feel included, but I feel like it's not for my burns. I think it's more "you're too big to hang"-type of situation because I'm a plus-size influencer. I don't feel like I fit into that bubble of Black Girl Magic. It could very well be my burns, but it feels like it's more so to do with my weight.

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**Taylor:** I'm gonna say because I know who I am, and I know that I have a disability, I don't see myself represented in Black Girl Magic. I feel like people on social media probably see me that way, because they probably don't know the disabilities that I deal with.

**I:** What is your definition of beauty?

**Taylor:** My definition of beauty is more about what you feel about yourself on the inside, like your confidence.... If you're a good caring person, then I think you're beautiful.

**I:** Do you feel like you had that perception before your accident? Or did it mold your perception of beauty?

**Taylor:** I feel like I felt this way before, but my accident made me like 10 times more [sold] on it.

Some of these responses highlighted the internalized misogynoir that Black women have been subjected to in shaping our own notion of beauty and the problematic ways of how we even see each other, in a competitive way. Through these “aesthetically pleasing” depictions of Black culture and womanhood, we are subjecting ourselves to be interpreted and analyzed by the outside world. While the original intent of Black Girl Magic seems good, it can perpetuate a negative effect. This ties back into anti-Black rhetoric, or as Moya Bailey writes: “the ways anti-Black and misogynistic representation shape broader ideas about Black women[‘s]” beauty, despite Black women not being a monolith (Bailey, 2021, cover copy).

In sum, multiple respondents expressed their belief that inner beauty is more important than physical appearance. One of my respondents mentioned the *Black Women's Blueprint* movement, which seeks to protect Black women's sovereignty and dignity and promote healing. This respondent went on to say that Black women have, and forever will be, the blueprint for cultural trends in beauty, often imitated, but never duplicated. Another respondent spoke about colorism and *intra*-racial discrimination driving appearance norms in her experience. Yet, another respondent expressed feeling pressured to perform pitiable Otherness and not feeling supported by other Black women and fellow burn survivors when she flaunts her scarred body. Furthermore, two respondents shared their feelings of

marginalization by the *Black Girl Magic* project, mentioning their plus-sized bodies or recognizable disabilities as reasons for feeling excluded rather than so much their burn scars.

### *Valuing Oneself as a Whole Person*

#### *Vs. Media Objectification through "Inspiration Porn" or The Politics of Pity for Profit*

Being that I reached the interviewees via social media is an indication within itself that they use their social platforms to spread burn-survivor awareness on some level. As explained in the literature review, there are some implications to putting yourself “out there” on a macro level, when you do not look like the average person. Your story can be used to inspire or motivate others. In most cases, however, this exposure can bring pity upon you, or what happened to you becomes your “master status,” sociologically speaking. The term for this in disability studies is “inspiration porn”; wherein the abled look to disabled people for “inspiration, awe, tragedy, triumph, and pity; they also presume a non-disabled audience and engage ableist concepts” (Schalk, 2018, p. 101). I wanted to close out the interview by asking my participants how they feel about their social platforms, and the ways in which it has either benefited them or had a negative effect on them, as well if they feel that the label of a “burn survivor” superseded other aspects of their identity. In the words of the respondents:

**Afia:** Although I’ve been a burn survivor my entire life, I don’t tie that with who I am as a person, like it isn’t the highlight of my identity.... I even ask my friends... “How do you describe me to others?” and they usually respond with like character traits, like “Oh she’s so sweet and funny.”

**I:** How do you feel the media portrays [you] as a burn survivor?

**Afia:** Talk shows reach out to me all the time, and I always decline, because I know what comes with that They want the “pity” exposure, and I know how the media works. I want to tell my story on my own terms, to create my own narrative. Plus, these companies will profit from MY story, like “No, this is my life!”.

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**Karli:** There's the good and the bad with social media. I'm an introvert, so I try to share bits and pieces as I feel necessary.....But I do feel like there's so much more to my identity than being a burn survivor, and that's what I try to portray on social media. It is impactful that others feel inspired by my story.

**I:** Do you feel that there's a downside to being a "representative" of burn survivors in some way? Especially since your story is so public.

**Karli:** I guess the downside is that people are just mean, and it's so easy to pay attention to the negative comments, even with so many positive ones. I actually did a TED Talk, and I remember seeing all the nice comments and likes on the video, but there was a [few] dislikes and I was super fixated on that, like... "Who wouldn't like this?" Another downside is the inspirational porn. I hate it! I feel like it's harmful and dangerous, people feel so entitled to you and your story.... I like to take control of my narrative and my story.

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**Markeyla:** When I first made a TikTok, my initial plan was to just post cute pictures of myself. Then one day, I posted on the anniversary of my accident, with pictures and videos of myself in the hospital and it went BONKERS ....My motive then was to show people what I went through, but my motive now is to show what happened afterwards. I do get in my head about just being known as the "burn survivor girl." I wanna show people the grind of me getting to where I wanna be in life, like that's the burn survivor girl who wrote a book, that got a TV show, or podcast you know?

**I:** Do you feel like it's your permanent identity?

**Markeyla:** I feel like with survivor girls like us, we're gonna constantly be dealing with the battle of ourselves, because you know we have to be reminded of something that happened years ago. It's constantly going to chase us because it lives with us now, we just have to give it a good room, you know? We're gonna forever live with that.

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**Julie:** I don't want that [burn survivor] "title" to be attached to me or my life story because it's like, even if I make the news for lifting up a bus and saving children, it'll always be tied to like the pity of me being a burn survivor.



**I:** Have you had any experience with “inspiration porn?”

**Julie:** I remember when I was doing the news interviews and everything, they make it a point to have this pity on you and would make comments like “Oh my God, you’re still going out and dating and living life?” and I’m just like, “Why wouldn’t I?”

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**Taylor:** With social media, I think the good outweighs the bad, because I’m helping someone and someone is helping me, it’s like a support system.... Every once in a while, you’re gonna have someone with something negative to say, but then I remember that I’m helping others in some way.

It was clear that all participants conveyed an important message: they desire to be viewed as a whole person with goals and aspirations just like everyone else. It is crucial for us to understand that their identity is not just defined by their burned bodies, but they are individuals with unique personalities, dreams, and abilities. The interviewees also highlighted the media’s tendency to profit off pity, and how the media depicts burn survivor stories as inspiration. While the respondents acknowledged the importance of sharing their stories, it is vital to balance the narrative and focus too on showcasing their individual achievements and talents. It is also important to remember that being a burn survivor will always be a part of their life, and others should be mindful and respectful of a burn-survivor’s lived experiences. In the estimation of the respondents, social media, overall can be a vital space for support, but negative comments can still be encountered.

## CHAPTER V: CONCLUSION

In conclusion, the findings of this study help further demonstrate the unique experience of the specific group at hand; the Black woman burn survivor. The objective of this study was to explore the ways in which a very particular trauma experience that leaves physical scarring and/or disfigurement impacts multiple areas of life, centering this experience and identity simultaneously through the theoretical frameworks such as the looking-glass self and intersectionality.

Working through the supporting literature, I introduced my argument with the discussion of dominant beauty standards and the ways in which they are not inclusive of all women, particularly Black women. To back this claim, I incorporated literature that analyzes the politics of ugliness and the terminology that constitutes what is deemed attractive and disfigured. Likewise, I also shined a light on the implications of within-beauty standards in the Black community, and how at times it can be contradictory in its lack of capability to include ALL Black women under the frame of intersectionality. In a potentially self-righteous effort, we created a racial/knowledge-based movement that in SOME ways still plays into anti-Black rhetoric, creating with-group friction between Black women alike.

The experience of the traumatized Black woman cannot be examined without attention to the initial disruption of life, and the ways in which it is handled. This literature analyzes the impact of sudden life disruption, and how it alters one's identity of the self. All these women had their incidents/accidents at different points in their lives, that subsequently changed the trajectory of their life stories. One survivor was three years old when her accident occurred, and she kept reiterating that being a survivor is the only life she has ever known. The trajectory of her life compared to the others differs tremendously, because she grew up being socialized

to understand that she was different and had no sense of “normality” to contrast. Being that the other interviewees were burned in their early adulthoods, they had to compare the life they previously knew and lived, and ultimately re-route their lives and identities.

In the recovery process, Black women are subject to unfair and inadequate treatment at the hands of medical professionals. With so much adversity and disruption, there is a strong possibility of mental health struggles in the aftermath of the traumatic events. Further literature backs the claim that Black culture has involuntarily placed limitations on the ways in which Black women process and cope with trauma. Black feminist disability studies have informed us that there are many forces at hand that contribute to the marginalization of Black people, especially Black women, who experience higher rates of disability, and one of the disadvantages is lower lifetime earnings for Black Americans, leading to a shortfall of benefits from disability programs and insurance simultaneously. As some of my participants mentioned, their struggle to make ends meet from the lack of benefits they were able to receive hindered them from being able to focus on their healing in its entirety, but instead they were focused on making money. Moreover, I found that whatever little benefits they received or money they made was not used to seek mental health resources. There needs to be a call to action to provide mental health services for those who experience traumatic injuries, ensuring these systemic barriers do not become the be-all and end-all. Two of my respondents were very open about how mental health professionals helped them a great deal, with one joining a support group for burn survivors. One potential method of healthy intervention is integrating burn survivors with (other) burn survivors, specifically introducing Black women burn survivors to *other Black women* who are burn survivors.

Intersectionality reveals to us that there is a “framing problem” that excludes all the “isms” (racism, classism, sexism, cis-heterosexism, and ableism). The focused -isms of this study revolve around race, gender, and disability (and class to some extent). There are different domains that intersectionality encompasses, such as interpersonal, disciplinary, cultural, and structural. The interpersonal domain focuses on the individual and societal interactions, and the literature and findings suggest that Black women who have been burned have a harder time “returning” to everyday life. Under the disciplinary domain, the Black woman’s experience is regulated through our social positions regarding systemic oppressions. The literature tells us that both culture and media outlets can create demeaning narratives about us through feel-good stories and “pity parties,” reducing us to only having one identity: a burn survivor. The last domain, structural, highlights the institutional limitations that the Black woman burn survivor is subject to as a result of physical scarring and or disfigurement, which embodies Black feminist disability studies’ take on economic and social impacts faced by Black disabled women.

Lastly, the looking glass self tells us that our perception of ourselves is a direct reflection of how others perceive us, therefore forming our ideas of identity. Anthropology studies have examined this in cultural contexts, and it is believed that the “self” is split into two categories; normative and alternate, and the literature suggests that Black women burn survivors will be placed in the alternate category, as that is the space in which meanings of the self are subject to change. This study in its totality has demonstrated the ways in which trauma can, and has been placed at the intersection of race, gender, and disability, which leads to the alternate view of the self.

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## APPENDIX A: INFORMED CONSENT LETTER

You are being asked to participate in a research study conducted by Bree McCall (co-principal investigator) and Jason Whitesel (principal investigator) from the Sociology and Anthropology department at Illinois State University. The purpose of this study is to analyze the trauma response of Black women that are burn survivors.

### **Why are you being asked?**

You have been asked to participate because you identify as a Black woman and are a burn survivor with physical scarring/disfigurement over the age of 18. Your participation in this study is voluntary. You will not be penalized if you choose to skip parts of the study, not participate, or withdraw from the study at any time. You are ineligible to participate if you are currently within the European Economic area.

### **What would you do?**

If you choose to participate in this study, you will be asked a series of semi-structured questions about your life experience before, during, and after your burn incident. Your involvement in this study will last approximately 1-2 hours, in a 1:1 interview via Zoom or a video recording feature. All interviews will be recorded and stored.

### **Are any risks expected?**

Potential risks could be some level of emotional discomfort, as the subject matter of the interview questions could be triggering. To reduce these risks, we can take breaks, you can refuse to answer particular questions, or you can choose to withdraw from the research study entirely.

### **Will your information be protected?**

We will use all reasonable efforts to keep any provided personal information confidential. All interviews will be saved and stored to a personal One Drive. Information that may identify you or potentially lead to reidentification may be released to individuals that are not on the research team. The results of this research study will be published in a completed thesis project.

However, when required by law or university policy, identifying information (including your signed consent form) may be seen or copied by authorized individuals.

### **Could your responses be used for other research?**

We will not use any identifiable information from you in future research, but your deidentified information could be used for future research WITH additional consent from you.

### **Who will benefit from this study?**

This study will benefit current/future students and scholars, as it is helping fill a gap in the literature pertaining to the intersection of race, gender, and a form of disability (scarring/disfigurement.)

### **Whom do you contact if you have any questions?**

If you have any questions about the research or wish to withdraw from the study, contact Bree McCall at 309-232-0267, email ([bjmcca2@ilstu.edu](mailto:bjmcca2@ilstu.edu)) or Jason Whitesel email ([jawhit6@ilstu.edu](mailto:jawhit6@ilstu.edu))

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If you have any questions about your rights as a participant, or if you feel you have been placed at risk, contact the Illinois State University Research Ethics & Compliance Office at (309) 438-5527 or [IRB@ilstu.edu](mailto:IRB@ilstu.edu).

**Documentation of Consent**

Sign below if you are 18 or older and willing to participate in this study.

Signature \_\_\_\_\_ Date \_\_\_\_\_

Your signature below indicates that you agree to be recorded.

Signature \_\_\_\_\_ Date \_\_\_\_\_

You can print this form for your records.

## APPENDIX B: INTERVIEW GUIDE

### Demographic

1. What is your name? (Do you wish to remain anonymous for this research report? Would you like to suggest a pseudonym for yourself, or should I choose one?)
2. How old are you?
3. Where are you from?
4. What's your occupation?
5. Where did your accident take place?
6. How do you refer to yourself as a burn survivor, burn victim, victim-survivor, or something else?
7. Tell me about the circumstances surrounding your burn injury? Was the timing of the injury meaningful in any way to your biography, social development, etc.?

### Disability/Injury

1. As a person living at the intersection of three marginalized identities (Black/woman/burn survivor), does disability justice play any role in your lived experience? If yes, how so?
2. After the burn event, how would you rate the quality of healthcare you received? Do you have any comments on positive and/or negative experiences with the healthcare system as a Black woman burn survivor? What is the nature, extent, and duration of your treatment like? How easy or difficult was it for you to access the care you needed? Were there any barriers to specialized treatment you needed?
3. How severe are your burns (1<sup>st</sup>, 2<sup>nd</sup>, 3<sup>rd</sup> degree)? How much of your body was affected?
4. How would you describe your appearance *before* and *after* the burn incident?
5. Have you ever considered or undergone plastic surgery to cover up your scars? If so, please explain.
6. Have you (or do you) ever tried to conceal scarred areas of your body and why?

### Emotional/Psychological

1. Please briefly describe what you can recall about your accident to the best of your ability.
2. What was it like to see yourself in the mirror for the first time as far as you can remember?
3. After the burn incident, how did it disrupt your life?

4. How would you characterize the level of your injury in terms of its visibility, impact on you physically and mentally, and your performance of various social roles?
5. How did your family and/or friends react after?
6. What was your experience like at school or work? I.e., do you remember being welcomed, accepted, bullied, ridiculed, avoided, rejected, or other?
7. Can you share any experiences with appearance-based discrimination?
8. Have you ever encountered subtle snubs regarding your appearance, or your story being consumed as inspiration? Can you explain what happened, and how you handled that situation?
9. Discuss any mental health issues you experienced as a result of your accident.
10. Discuss some of the ways you dealt with any insecure feelings you had after your accident
  - a. Can you tell me about your support system? I.e., how you felt encouraged (discouraged) to talk about your sense of self, your fears?
  - b. In what ways have you felt you were given space to be vulnerable with a physical scarring or disfigurement?
  - c. If you sought help from a mental health professional, what was that experience like?
  - d. What are some of your coping mechanisms?
  - e. What are some of the positive affirmations you use?

### **Analytical**

1. What is your definition of “beauty”?
2. Discuss your sense of being beautiful...
  - a. Before vs. after your accident...?
3. Do you think the social effects of scarring vary by race and gender? If yes, how so?
4. Discuss any challenges you have experienced in navigating womanhood as a burn survivor.
5. Discuss your experience of any negative reactions from the Black community you may have had.
6. In what ways do you or don't you see yourself represented in *Black Girl Magic*?
7. Do/did depictions of Black women as resilient have any effect on your ability to process the trauma of being burned or your openness or reticence to identify as socially or physically disabled?
8. What are some ways you have found to successfully receive validation, approval, or acceptance from others?
9. Discuss the ways that you feel (or don't feel) you are seen and accepted in social settings.
10. Discuss ways in which you have experienced social anxiety.

11. Do you engage with social media as a platform for burn-survivor support or to promote awareness? If so, tell me about it.
12. What advice would you give to another Black woman who is a burn survivor?