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Skin Deep: Body Modification and Agentic Identities Among Women with Skin Conditions

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by
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ABSTRACT

Skin Deep: Body Modification and Agentic Identities Among Women with Skin Conditions

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This study explores processes of identity construction among women who have skin conditions and body modifications. Analyzing seven semi-structured qualitative interviews, the author examines how individuals affected by skin conditions employ body modification practices to organize their identities and promote feelings of agency across both personal and social domains. Engaging a Bakhtinian dialogic lens, the author argues that body modification may operate as a de-stigmatization strategy that supports individuals with skin conditions in cultivating a sense of self-determination and bodily sovereignty. Shaped by grounded theory, this study's findings trace relationships between body modification and the development of agentic identities among women with skin conditions. Confronted by medical, physical, and social disenfranchisement, women affected by skin conditions may implement body modification practices to navigate treatment, incorporate their conditions, and negotiate their relationships. The author additionally suggests implications for the application of body modification practices as somatic therapeutic modalities.

DEDICATION

For the seven women who shared their stories with me and for anyone growing comfortable in their own skin.

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Chapter 1. Introduction

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In the 15th century, a Japanese shogun broke his favorite tea bowl and sent it to China to undergo repairs. When the bowl later returned to him, however, it had been placed back together with metal staples. Displeased with his once-beautiful bowl's new appearance, the shogun recruited craftspeople far and wide to develop a more artful and unique way of repairing the cracked ceramic dish (Bachar & Storms, n.d.). Seeking to accomplish the shogun's challenge, the artists tried to repair the bowl's imperfections and elevate its aesthetic beauty beyond its original state (Pace, 2018; Scherb, 2018).

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I felt broken the day my vitiligo started. The tent was colder than I had expected the night before in the desert, so I slept in the car with the dog on my lap, facing East. As the hot sun rose over the Sangre de Cristo mountains and shined through the windshield, it burned my face, until I woke up hours later, sufficiently in need of aloe vera. This sunburn was different than others I had gotten in the past, though. Rather than turning my skin bright red, the pigment in my face instead had just mysteriously vanished. My forehead turned completely white. I then waited month after month for my skin color to return, but it never came back. My two-toned face had become foreign to myself and I felt like a broken vessel, as if all of me had somehow shattered into pieces.

I had ventured to the desert that summer for its wide-open spaces, hoping to fill myself with all of Southern Colorado's golden nothing. My mom had died back when there was still snow on the ground and I had just been through the most traumatic and stressful year of my entire life. Seeking rejuvenation, I ventured to the sun-soaked dunes to clear my head, but instead, part of my head changed forever.

For the next several years, I embarked on a long and arduous medical journey. A dermatologist diagnosed me with vitiligo, an “irreversible condition” that causes the skin to stop producing pigment (hypopigmentation). The allopathic medical community then supplied no answers for me about the cause of this condition. Likewise, most medical providers described the treatment options as ineffective, impermanent, and potentially carcinogenic. Even with repeated and costly laser exposure and ultraviolet band therapy, my vitiligo would most likely continue spreading across my body. Confronted with this lack of viable medical choices, *acceptance* felt like my best and only worthwhile option.

Relinquishing control of my appearance has been a challenging process. Multiple years passed after my diagnosis before I had met another person living with the same condition. The psychological distress of isolation, stigmatization, and loss of bodily agency associated with vitiligo significantly impacted my mental health. Although I underwent radical changes in my lifestyle that helped me manage my concomitant health problems, I still continued to struggle with body-image issues. Irreparably damaged, I felt fractured from my former self. Then, on a whim while traveling in Portland, Oregon, I got my septum pierced and everything changed.

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As the craftspeople worked to repair the shogun’s broken tea bowl, they joined the cracked pieces of ceramic using lacquer resin, flaked with powdered gold (Ellison, 2012). Although debated by scholars, this moment is often described as the birth of the Japanese art form of kintsugi (Cort, 2008). Through kintsugi, or “gold joinery,” the craftspeople developed a “method of repairing broken pottery by highlighting the *mended cracks with precious metals and lacquer" (Scherb, 2018, p. 4). Celebrating the work of art that they had created, the craftspeople returned the tea bowl to the shogun more beautiful than before (Ellison, 2012.)*

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After affixing a shiny gold ring in my nose, I immediately felt an increase in confidence. It was the first time I had felt as if people saw something other than the vitiligo across my face. Meanwhile, the gold nose ring seemed to complement the white color of my vitiligo in an aesthetically pleasing way that felt distinctive, unique, and personally special. Although I had tattoos prior to the development of my skin condition, the tattoos that followed have also helped me to feel more at-home in my body and more integrated with my appearance. Additionally, I was offered a tattoo apprenticeship prior to my acceptance into graduate study and have begun a large-scale tattoo project on my body, peripheral to this research.

While multiple tattoo sessions have poured ink like golden lacquer between the fragmented parts of my skin, this study has operated as a kiln of sorts for me. Throughout this project's completion, I have been redefining my personal process journey of *healing*. My own therapeutic experiences with vitiligo, concomitant health issues, and body modifications have inspired me to explore how people with skin conditions and other markings of the skin relate to and make meaning from their body modifications. Viewing body modification practices as potential somatic avenues for therapeutic intervention, I sought to explore whether aspects of my personal experience might apply to other skin conditions beyond vitiligo.

The following chapters are my attempt at tracing the golden threads that join extremely unique personal narratives of living with both skin conditions and body modifications. At times, this study's interviews felt jagged, sharp, and scattered. Other times, the conversations bonded together, smooth as clay, and precious. I attempted to treat each of this study's contributors as distinct individuals with their own lines of fracture, their own metal staples, and their own strategies they developed to feel irreplaceably whole.

Chapter 2. Literature Review

The Greeks coined the term *stigma* “to refer to bodily signs designed to expose something unusual and bad about the moral status of the signifier” (Goffman, 1968, p. 1). Goffman (1968) notes that the concept later acquired two additional metaphorical layers: “the first referred to bodily signs of holy grace that took the form of eruptive blossoms on the skin; the second, a medical allusion to this religious allusion, referred to bodily signs of physical disorder” (Goffman, 1968, p. 1). In the word’s contemporary usage, however, an individual’s stigmatized status may present with varied degrees of visibility, concealability, and social influence. Although the term *stigma* currently connotes disgraces beyond the bodily evidence of moral failure, its etymology originally pointed to the social discreditation of markings of the skin.

Skin conditions, such as vitiligo, alopecia, acne, psoriasis, eczema, rosacea, and seborrheic dermatitis currently affect millions of people in the United States (Center for Disease Control and Prevention, 2020; Harvard Health Publishing, 2019; National Alopecia Areata Foundation, 2020). Although some of these conditions may be treated with symptom-management protocols, many skin conditions, such as vitiligo and alopecia, are categorized as “irreversible” and “incurable” disorders. The majority of individuals with stigmatizing skin conditions develop these illnesses in early adulthood, which can have a significant impact on their psychological wellbeing. Many patients describe becoming unrecognizable to themselves in the mirror and struggle with maintaining a feeling of physical continuity (Beckett, 2015). Developing largely outside of their control, markings of the skin influence a heightened sense of affected peoples’ otherness and physical difference. By voluntarily altering physical appearance, body modifications may assist people in repositioning their sense of bodily agency.

Each of the skin conditions examined in this study may constitute or accompany the diagnosis of an “autoimmune illness.” Sometimes referred to as “Western diseases,” autoimmune illnesses affect nearly 24 million people in the US (National Institute of Environmental Health Sciences, 2020). The blanket term “autoimmune illness” refers to a wide range of dysregulated bodily responses triggered by a variety of environmental stressors, pollutants, systemic acidosis, or chronic lymphatic stagnation (Ehret & Spira, 2015; Morse, 2012; Nakazawa, 2008; Velasquez-Manoff, 2013). Although the allopathic medical complex circulates the disputed diagnosis of “autoimmune illnesses,” it fails to materialize a cure, leading many patients on a vulnerable search for medical salvation (Berlant, 2011). Meanwhile, Western medical discourses broadly present the symptoms of autoimmune illness as a series of “attacks” in which the body turns against itself. This dissociative, self-effacing conceptualization of immunology may threaten the stability of one’s personal identity and/or self-concept (Goffman, 1968). Caplan (2010) writes, “the skin can be seen as an interface that articulates the relationship between internal and private aspects of the body on the one hand, and external and public aspects on the other, and which enables a form of communication between them” (p. 120-121). For individuals with skin conditions, however, this dialogue may present unique and unwelcome challenges. While managing autoimmune illness traverses already fraught medical territory, stigmatized skin conditions may trouble the social embeddedness of embodiment.

Cultural Expressions of Body Modification

The earliest evidence we have of tattoos is a thin pencil mustache inscribed on the upper lip of a 7,000-year-old mummy from the Chinchorro culture of Peru (Krutak, 2012). Unsurprisingly, this ancient body modification attends to the cosmetic. The second oldest evidence of tattooing, however, concerns the medicinal. Ötzi, the 5,300-year-old “Iceman” mummy from the Austrian Alps, wore 57 tattoos, 80 percent of which “overlap with classical Chinese acupuncture points utilized to treat rheumatism, a medical condition that plagued the Iceman” (Krutak, 2012, p. 23). Accompanying these windows into tattooing’s archaic past, anthropological ethnographies constellate a colorful array of socially-reinforced body modification traditions. For example, in indigenous cultures across Polynesia, Micronesia, and New Zealand, tattoos display lineage affiliations and rites of passage (Cann, 2014). Similarly, First Nation North American tattoos and body piercings “functioned to initiate individuals into adulthood, cure bodily complaints, reflect social status, document martial achievement, and to channel and direct supernatural forces” (Krutak, 2017, p. 211). Nlaka’pamux tattoo artist Dion Kaszas notes that body modification was practiced “by almost every indigenous nation across Canada and the United States” (Krutak, 2017, p. 212). Generally speaking, body piercings and tattooed markings of the skin help to “tell the world who one is and define one’s position within society” (Cann, 2014, p. 52). Contrary to many Western, colonialist, and classist designations, archeological and anthropological literature evinces tattooing’s social and personal import.

Over the past two decades, body modification has become an increasingly popular practice in the United States. One study of American college students found that 60% of women and 42% of men were pierced. Additionally, this study estimated 10% of Americans were tattooed (Kaatz et al., 2008, p. 40). Considering that the tattoo industry has climbed to a $2 billion valuation in the United States and boasts over 47,000 businesses, it may be sensible to assume that these percentages have grown since 2008 (Dobie, 2019). Alongside its unprecedented popularity, body modification may provide a way for individuals to regain a feeling of control over their bodies. When confronting purportedly incurable diagnoses, body modification practices may offer psychic relief for individuals as they grapple with their changing appearance.

Conceptualizing the Body

In addition to its diverse sociocultural meanings, "the body" also comprises a domain of academic research developed by scholars and theorists across a wide range of fields (Pabst, 2015). In reviewing various conceptualizations of the body, two primary themes emerge in relation to this study: (1) the body as an ongoing personal "project" and, (2) the body as an "absence" that remains in the background of one's awareness until various issues cause it to inconveniently "dysappear" (Leder 1990; Shilling, 2003). In tandem with these parallel discourses, the decision to undergo body modification might engage what Wegenstein (2012) terms "the cosmetic gaze." This notion envisions the body as something that can be improved upon and molded according to one's will. Considering conceptualizations of the body and "the cosmetic gaze" in light of this study may elicit some of the motivations that encourage individuals to modify and inscribe their bodies (Schildkrout, 2004; Wegenstein, 2012).

Body as Project & Absence

Academic discourses have widely conceptualized the body as the fundamental ground through which people cultivate their identities (Butler, 1989; De-Preester, 2011; Derrida, 2005; Goffman, 1968; Merleau-Ponty, 1945; Sartre, 1943). Coupled with this ontological scaffold, scholars have framed the body as an autobiographical "project," portraying body management practices as epistemological emblems of an individual's "developing sense of self" (Shilling, 2003, p. 187). Similarly, the tattoo industry has incorporated the term "project" to refer to large-scale tattoos or tattoo collections. The notion of the body as a "project" positions the modification and metamorphosis of the body as both the primary vehicle and vessel of self-awareness (Giddens, 1991). In contrast, Leder's (1990) conception of the "absent" body highlights the body's disposition to perceptually remain in the "corporeal background" (Leder, 1990, p. 1). As the individual stabilizes physical homeostasis and regulates towards emotional equilibrium, the body lingers in "corporeal absence," unless physical or social experiences cause it to inconveniently "dysappear" and command one's direct attention (Leder, 1990, p. 26). While the body may tend to fade from awareness, individuals with stigmatized skin conditions may experience bodily "dysappearances" in disproportionately greater frequency and severity via physical, social, or psychological disruptions. The volitional character of body modification practices as "project" starkly contrasts the compulsory nature of skin conditions that interrupt a prevailing sense of bodily "absence." Through the engagement of this juxtaposition, however, individuals with body modifications and markings of the skin may enact an embodied hybridized space, presenting the body at once as both an arbiter of identity-threat and a pathway towards self-understanding.

Customizable Bodies and the Cosmetic Gaze

While body modification practices wrestle with the tension between contemporary notions of the body as both a self-referential "project" and an "absent presence," the vitality of the esthetic industry elicits the prevalence of a more commercially grounded vantage point (Ewald, 2018). This view, which Wegenstein (2012) terms the cosmetic gaze, envisions the body as a customizable, mediated form that can be improved upon and shaped. In response to the irreversible nature of many skin conditions and markings of the skin, individuals casting the "cosmetic gaze" upon themselves may resort to make-ups, creams, or other products of "concealment." This desire to "improve" one's markings of the skin may operationalize body modification as a means of elevating one's "spoiled appearance" or achieving "symbolic self-completion" (Goffman, 1963, p. 42; Schouten, 1991, p. 412). Mun (2012) demonstrated that many tattooed women reported feeling an increase in confidence after being tattooed. This increase in body confidence, however, for the individual with a skin condition, may derive, as Goffman suggests, from the process of "impression management" (1963). Body modifications may highlight different aspects of one's body that can draw attention away from other, less favored markings of the skin. Similarly, body modifications may "compensate" for stigmatized conditions by "improving" the appearance of affected areas or highlighting other areas of the body (Shih, 2004, p. 197).

Representations of Skin Markings and Body Modifications

While academic discourses broadly figure the body as the primary interface through which the individual relates to their social environment, representations of skin markings and body modification practices provide insight into the context of this study's historicultural moment (Butler, 1989; Foucault, 1995; Lacan & Fink, 1999). The academic landscape ambivalently presents individuals with skin markings as both the victims of stigma and the cosmetically disfigured (Kent, 2000; Porter, 1991). Similarly, media representations of body modifications illustrate such practices as indicators of social capital as well as mental illness (Pitts, 1998, Halberstam, 2017). Media portrayals of body modifications may differ across practices, prompting various degrees of pathologization and stigmatization (DeMello, 1995). The interplay between academic and media representations of skin markings and body modification practices displays the cultural treatment of affected individuals as they construct and shape their embodied identities.

Research Representations of Skin Markings

Researchers studying individuals with markings of the skin have examined the psychosocial impacts of externally “enacted stigma” and internally “felt stigma,” as well as the various “impression management” strategies that people with skin conditions employ to mitigate these challenges (Becker 2016; Goffman 1963; Kent 2000; Porter 1991). The expression and implementation of these processes, however, may differ across skin conditions. In particular, Becker’s (2016) study of stigmatization-related stimulus bias in individuals with alopecia and psoriasis indicated that people with different skin conditions may display varying degrees of perceived stigma or self-stigma. For example, research participants with psoriasis appeared to be more affected by disease-related cues, such as being labeled “contagious,” than participants with other skin conditions. Meanwhile, individuals with alopecia were more responsive to social threat-related stimuli in which the individual displays an elevated concern for stigmatization and criticism from others. Furthermore, Porter identified the distinct challenges different racial groups face in reaction to vitiligo, such as the perceived loss of one’s racial identity. Concerns surrounding racial identity were reported in greater frequency among black participants than white participants (Porter, 1991, p. 199). The visibility and prevalence of the skin condition throughout the body may also indirectly impact affected individuals. For example, the appearance of a skin condition on the face may provoke increasingly heightened levels of stigmatization than in more private, concealable areas of the body. Gender, age, and visibility of the condition may also indirectly influence the degree of disturbance felt by individuals with markings of the skin.

Despite the idiosyncratic and emotionally sensitive experience of having markings of the skin, some researchers have broadly labeled such individuals as having an “impaired appearance, cosmetic handicap, and/or disfigurement" (Kent 2000; Porter 1991). This terminology has the potential to exacerbate the stigmatization these individuals already experience by imposing upon the research an essentialized beauty standard that excludes other valuations of beauty endorsed by research participants themselves. Additionally, this process of favoring normative beauty standards while pathologizing skin conditions as "disfigurements" can trouble de-stigmatization strategies that affected individuals may employ. Shih (1991) examined how stigmatized individuals have successfully overcome stigmatization by valuing criteria that do not place them at a disadvantage. For example, individuals with skin conditions may strategically devalue and critique beauty norms that laud physical perfection. Crocker and Major (1989) similarly illustrated how stigmatized individuals tend to discredit disadvantageous criteria and, instead, compensate by prioritizing more compatible criteria. Accordingly, individuals with skin conditions may selectively favor different aspects of their identities that promote their social credit, such as displaying a sense of humor or various talents (Crocker & Major, 1989). The academic use of the terminology of "impairment," however, reinforces beauty valuations that research participants themselves may seek to demerit. Countering the application of stigma management strategies, academic discourses of "impairment, disfigurement, and handicap" imply that an ideal standard of beauty exists to which the individual under examination can be contrasted or compared (Bochner, 2000, p. 267).

Media Representations of Tattooing

In similarity to research portrayals of skin markings, mainstream media often frame and represent body modification practices with a dualist gaze of both "repugnance and fascination" (Pitts, 1998, p. 70). Pitts-Taylor examines how many mainstream media outlets portray body modification as an act of "self-mutilation," situating modification practices as a mental health issue. In doing so, these characterizations create a correlation between “tattooing, scarification, piercing, and branding” and “other social problems, especially those which express a lack of control, such as drug addiction, bulimia, and crime” (Pitts, 1999, p. 296). Likewise, Steward (1990) suggests that popular media reinforce stereotypical connotations of tattooing with criminal or deviant behavior. While tattooing is often mediatized as an indicator of an underlying psychosocial pathology, Adams (2009) also identified verbiage in popular media that associates body modification with health risks, such as infections and bloodborne pathogens. The pathologization of, and health risks correlated with, body modification practices may operate as additional sources of stigmatization for individuals with skin conditions.

Gender and age may also influence the representation of body modification in popular media. Adams (2009) explored how media representations and gender frames position tattooing as “less normatively acceptable for women than men while extolling the number of women becoming tattooed, often in a highly sexualized manner” (p. 116). Adams noted that the exhibition of conspicuous tattoos on the lower back, navel, and breasts accentuated once-hidden areas of flesh, often marked by sexual associations. Consistent with the findings of Davila (2005) and DeMello (1995), Adams found that such sexualization of the tattooed woman in various media representations signifies not only a potential dimension of stigmatization, but also, and perhaps conversely, a representation of tattooing as a benign expression of taste and fashion rather than criminal affiliation. Body modification practices in mainstream media are characterized by a mixed and often contradictory range of cultural impulses.

Representations Across Body Modification Practices

Extending this analysis of cultural ambivalences, researchers have examined how media representations differ both within and across body modification practices. Atkinson (2004) illustrated mainstream media's mixed construction of tattooing as both a fashionable lifestyle choice and social problem. By investigating articles that discuss tattooing as an elevated fine art and its increasingly specialized professionalization within the esthetic industry, Atkinson positions tattoos as both social and consumer signals. This advanced infrastructure of the body modification industry legitimizes tattooing as not only a personal consumer lifestyle option, but also as an increasingly accepted occupation. Furthermore, DeMello's review of media representations examined characterizations of tattoos as an articulation of "personal aesthetics, individuality, and spirituality or personal growth" (1995, p. 42). DeMello specifies not only that mainstream media present tattooing as a practice that reinforces the middle-class values of consumer choice and expression of individuality, but also that mainstream media simultaneously omit associations with deviant behavior and class affiliation. This variability amongst research findings in the academic discourse reflects the clashing and stigmatized portrayals of tattooing in popular culture.

Body piercing, on the other hand, often evokes more problematized media representations. While cosmetic surgery and tattooing are often positively framed as choice-driven lifestyle options, Adams (2009) observes that piercing is negatively represented as an unhealthy and expressly deviant practice. Noting how both health risks and markers of deviance associated with cosmetic surgery and tattooing are often downplayed, while risk factors related to body piercing are overstated, Adams illuminates the key differences of semiotic representation between tattooing and body piercing. While tattooing is often presented as a significant and meaningful practice, body piercing is generally represented as a potentially dangerous fad (Adams, 2009, p. 117; Samantha et al., 1998). Ferreira (2011) similarly found that the location and size of one's body modification may influence the extent of stigmatization they experience.

For example, facial tattoos and genital piercings often garner associations of criminal activity and sexual deviance respectively. Ferreira (2011) further notes that large-scale tattoo projects, in contrast to smaller tattoos, may be treated with a greater degree of stigmatization and mental health concern (p. 325). These media-framing devices echo preexisting social opinions, while simultaneously shaping emergent popular understandings.

Dialogical Lens

Although a range of sociocultural locations have classified body modification as a marker of "deviance," Russian philosopher Mikhail Bakhtin's theory of "dialogism" may situate body modification practices within a multiplicity of intersecting discourses. Bakhtin (1984) insists that meanings are negotiated through a plurality of unmerged consciousnesses, in a multi-voiced "dialogical" reality, as opposed to residing within a single, "monological" perspective. To Bakhtin, "truth is not born nor is it to be found inside the head of an individual person; it is born between people collectively searching for truth, in the process of their dialogic interaction" (p. 15). Applying this "dialogical principle" to tattooing and body piercing may dispel monological images and narratives of body modification practices as abject social problems. The multiplicity of potential meanings associated with and projected by body modifications exemplifies Bakhtin's description of the "polyphonic" and "heteroglossic" text, in which a single text may contain matrices of complementary and contradictory meanings. Inscribed bodies invoke "a plurality of consciousnesses, with equal rights and each with its own world," that may "combine but are not merged in the unity of the event" (Bakhtin, 1984, p. 33). This plurality of perspectives, however, may concomitantly promote dominant cultural vantage points. In tandem with challenging various social norms, body modification practices may also concretize and enshrine socially-reinforced values and standards.

Dialogic Expressions of Body Modification

Applying a Bakhtinian dialogical lens to body modification discourses exposes heavily tattooed bodies of knowledge. Departing from monologic representations, researchers have explored body modification's strategic and subversive import in personal, social, and political arenas (Atkinson, 2004; Davis, 1995; Gimlin, 2002; Langman, 2008). In this regard, body modifications may offer individuals with skin conditions an extended range of motion as they confront stigmatization and undermine its governing norms. This study strives to marry these previously separate areas of research to develop an understanding of body modification as a potential de-stigmatization strategy that assists processes of personal and social identity construction.

Body Modification as Pro-Social Behavior

Advancing an attention to tattooing's normative functions, some researchers have positioned tattooing as a pro-social behavior. In outlining the pro-social aspects of tattooing, Atkinson (2004) adopts the sociological concept of "figuration." This framework envisions social group membership as a nexus of interdependent webs of social interaction. Atkinson identifies common themes that present tattooing as a learned cultural habit that emboldens group membership identities and social belonging. Similarly, Santos (2009) examines how Chicano male tattoo artists operate as "cultural gatekeepers of what it means to be a cultural insider" and centralize "expectations of how femininity, class, race/ethnicity, and sexuality should be done" (p. 92). Meanwhile, their Chicana female clients embody and signify social agency by challenging the "status quo and subverting the power imposed on them by men who are tattoo artists" (Santos, 2009, p. 92). In this sense, tattooing enacts a Matryoshka doll of conversant cultural inclinations. Rather than engaging an irreverent dynamic, tattooing enacts a dialogic critique of popular body norms (Bakhtin, 1984). Accordingly, tattoos often display and project an acceptance of established cultural standards. Specifically, studies trace how tattooing often facilitates a performance of "toughness," reinforcing masculine gender norms (Halberstam, 2017). While broadly regarded as indicators of social deviance, tattoo projects may also signify varied expressions of normative "social capital" (Atkinson, 2004, p.129). A tattooed individual's body, then, may project multiple group alignments at once. Despite, or perhaps because of, tattooing's "polyphonic" status, "the tattoo offers itself as a profuse and even delicate mechanism for the production of subtly intertwined meanings" (Bakhtin, 1984; Caplan, 2010, p. 137).

Body Modification as Affect Management Practice

Transcending mere cosmetic improvement, tattooing may semiotically function as an "affect management" strategy (Atkinson 2004). In opposition to representations of tattooing as an indicator of psychic dysregulation, Atkinson presents tattooing as a practice of inscribing controlled representations of emotional experience onto the body. As affect management strategies, tattoos may multi-directionally aid various emotional processes, by functioning as memorials for dead loved ones, rites of passage for personal transformation, or reliquaries for autobiographic narrativization (Atkinson, 2004; Mun, 2012). Cann (2014) writes:

> The development of tattooing is one way to carry the dead around with us, while also making the status of the bereaved clearly evident to those around them . . . simultaneously establishing the identity of the bereaved in a fixed and permanent way in a society that denies the corpse and no longer gives space for grieving. (p. 49)

Similarly, Caplan (2010) examines how tattoos operated as interpersonal locations for both personal and communal memory in the wake of the September 11 attack on the United

States in 2001. Research additionally suggests that tattoos may assist individuals in managing expressions of emotion, sexuality, grief, and social critique (Atkinson, 2004; Shih, 2004). Tattooed skin may function as a "[memory place] for reconstructing the person as a locus of remembered events," while simultaneously engaging a site for the negotiation of emotional experiences (Gell, 1993, p. 36).

Marginal Embodiment

Inscription of the internal emotional state contests dominant theorizations that conceive of the body as an *a priori* or a "ground upon which cultural significations are inscribed" (Butler, 1999, p. 176). In opposition to representations that present the body and its inscription as separate statuses, tattoos can reinforce the notion that there are only "already constructed, discursive bodies—bodies integrated to a greater or lesser extent in systems of meaning-construction and communication." Both skin conditions and body modifications, "inhere insecurely in the skin as an organ possessing both surface and depth, conducting an exchange between what is exterior and what is interior to skin and body alike" (Caplan, 2010, p. 144). Antagonizing the inconsistency between internal and outward bodily affect, the tattoo produces a "paradoxical double skin [such that] the skin and the tattoo are integrally one and indivisible" (Gell, 1993, p. 38). In applying Butler's (1999) analysis of the substantively empty interior self, this discordance challenges the "ontological status of identity apart from the various acts which constitute its reality" (p. 178). Butler (1999) writes: "Such acts, gestures, enactments, generally constructed, are performative in the sense that the essence or identity that they otherwise purport to express are fabrications manufactured and sustained through corporeal signs and other discursive means" (p. 178). Body modification practices and markings of the skin physically inscribe the body with discursive meaning, opening the membrane between the interior and exterior self.

Embodying ambivalences and ambiguities at the margins of personal and social identity, skin conditions and body modifications can resist and revise conceptualizations of selfhood that may galvanize stigmatization. In this sense, physical beauty cannot be reduced to terms such as "impaired, handicapped, or disfigured," since cosmetic valuations "can be neither true nor false, but are only produced as the truth effects of a discourse of primary and stable identity" (Butler, 1999, p. 181). While skin conditions interrogate the borders of the self, they externally reveal internal states of health and wellbeing. That said, body modification, as an expression of affect management, and skin conditions, as transmuted interior cosmetic markings, subvert the distinction between inner and outer physical and psychic space. Thus, body modifications and markings of the skin trouble the fixity of beauty norms, somatically enacting Gell's (1993) suggestion that, "the skin may be . . . a third thing, between the alternatives of a screen that lets things through, or a slate on which things may be deposited" (p. 93).

Carnivalesque Bodies

Applying Bakhtin's (1968) concept of "carnival" as both a time of release and a container for social revitalization and cultivation, Langman (2008) contends that this permeability between the interior and outer self may have heightened sociopolitical implications. Langman suggests that body modifications stand as "criticism of and opposition to norms, practice, and appearance of the dominant society." Body modification practices engage the re-emergence of the carnival, which Bakhtin described as a germinal space in which a variety of social transgressions attain cultural legitimacy. As carnivalesque acts, body modifications constitute a means of claiming agency to "resist domination, invert disciplinary codes, and experience utopian moments"

(Langman, 2008, p. 657). For example, Craighead (2011) notes that heavily tattooed women might engage embodiment’s “subversive power to elevate female subjects from ‘object’ to active ‘participant’ within the consumerist-art-financial-embodied-identity exchange” (p. 42). This process of social critique, for individuals with skin conditions, however, may be a more emphatic experience. As Shih (2004) noted, stigmatized individuals may espouse strategic interpretations of the social environment to overcome stigma. Bodying forth these revisionary interpretations, modification practices may help create a form of human social configuration that “lies beyond existing social forms” for stigmatized individuals to rework their disadvantaged statuses (Bakhtin, 1968, p. 43).

Body Modification as De-Stigmatization Strategy

In concert with this analysis of group membership identity, several studies indicate that stigmatized individuals focus on multiple identities as a strategy to overcome stigmatization. Certain identities may be stigmatized in one social context, but not in another. Therefore, individuals can avoid the negative associations of one identity by focusing on a range of alternate identities (Shih, p. 180). Likewise, Davis (1995) and Gimlin (2002) show that women who underwent plastic surgery attributed their decision to a range of self-identity factors and pragmatic social efforts. Incorporating both Atkinson’s (2004) and Shih’s (2004) findings, it is reasonable to suggest that tattooed individuals who mark the variety of their group alignments and social capital may use their tattoos to focus on multiple identities as an empowering process against stigma. Furthermore, the significance of such group alignments and the support individuals receive from them may significantly aid the process of overcoming stigmatization. Porter’s (1991) research demonstrates this importance of social support networks in managing stigma. By emblemizing the capaciousness of one’s social identity, support networks may assist stigmatized individuals in reducing stigmatization and establishing diverse group membership alignments.

Conclusion

Many researchers have examined the impacts of stigmatization on people with skin conditions. Likewise, research abounds studying the psychosocial dynamics of tattoos. A significant gap, however, exists in the rigorous engagement between the two. While many researchers have explored the “meaning” of tattoos for cosmetically normative individuals, a gap remains in exploring the semiotic implications of body modification for individuals experiencing stigmatization of the skin. Furthermore, body modification’s association with deviance and mental illness have complicated research surrounding its viability as an assistive procedure for individuals experiencing stigmatization. The following analysis provides insight into body modification as a potential coping strategy in managing the emotional and social challenges of skin conditions. While many researchers have characterized skin conditions as “cosmetic handicaps” and “impairments of appearance,” this research study aims to situate beauty valuations less in the hands of the researcher than in the eye of the participant beholder. Additionally, this study may ratify dialogues in the medical field that position body modification as a strictly dangerous practice, while overlooking its potentially empowering benefits for stigmatized individuals.

Researchers have examined how body modification may multi-directionally negotiate discrepancies between notions of the body as “project” and the body as “absence.” The present state of the literature, however, demonstrates gaps surrounding how this relationship may apply to the experience of individuals with skin conditions. Although researchers have explored the effects of “stigma” and correspondent “impression management” strategies in individuals with markings of the skin, body modification has been generally overlooked as a potential de-stigmatization strategy. While body modification may operate as a physically-alterative "intervention in identity" (Davis, 2003, p. 74), individuals with stigmatized skin conditions may elect to undergo body modification "in an attempt to lessen or eliminate their experiences of bodily intrusion" (Gimlin, 2006, p. 704).

This research study seeks to answer the following two primary research questions. First, how do individuals with skin conditions or other markings of the skin relate to their body modifications? And second, what relationship exists between the social aspects of people's skin conditions (vitiligo, alopecia, psoriasis, etc.), body modifications, and the construction of identity? In the following chapters, I turn to participant narratives for insights into the interplay of skin conditions, body modification practices, identity construction, and the making of meaning.

Chapter 3. Methodology

This project emerged from a desire to amplify the voices of individuals with skin conditions and body modifications by sharing experiences that have been widely underrepresented in academic and medical discourses. My personal journey with vitiligo and a largescale tattoo project prompted me to explore how body modification practices might galvanize or reconstitute the relationships of stigmatized individuals with their physically embodied and socially embedded identities. Although previous studies have examined the interpersonal dimensions of skin conditions and body modification, the relationships between these two have not been thoroughly explored (Beckett, 2015; Ferreira, 2011; Pitts, 1999; Porter, 1991). Addressing these gaps in the literature, I sought to investigate how body modification may operate multi-directionally as a group membership identifier and prosocial de-stigmatization strategy. In order to understand the implementation of these strategies, however, I focused significant attention to interpreting how contributors conceptualized the effects of physical illness, medical disempowerment, and social stigmatization. Considering the idiosyncratic appearance, presentation, and experience of stigma, this study employed qualitative research methods to elicit and magnify the subjective perceptions of the participant contributors and researcher. Incorporating a narrative approach, this project simultaneously acknowledged and valued the instability of these personally reported experiences as both the prerequisite of research and the emblem of knowledge production.

Narrative Framework

Narrative reflection engages a retrospective gaze, in which the participant looks backward in time, from the present moment, towards an episodic sequence of past events constitutive of a larger whole (Freeman, 1984). In hindsight, narrative seeks to organize what may have, at the time of occurrence, been defined by chance and randomness. Freeman (1984) writes, “The notion of chance, being tied to expectation or lack thereof, is predicated upon an essentially forward-looking perspective, a kind of stochastic unraveling of events through time (p.2). Furthermore, De Fina (2015) adds, “But to the extent that sense can be made, that events in their unfolding can be understood—perhaps even explained—after the fact, there is frequently the conviction that what has transpired does indeed possess a certain order” (p. 28). Accordingly, narrative’s retrospectivity seeks to make meaning from “the ineradicable asymmetry between the knowledge that derives from looking forward in time and that which comes from looking back” (Freeman, 1984, p. 14). Narrative interviewing activates unifying and interpretive faculties that encourage participants to author their experiences and to construct meaning from their unfolding.

This study employs narrative interviewing to generate retrospective reflections in participants who have historically been confronted with “aleatoric” challenges defined by notions of chance, accident, or unintended consequences (Gergen, 1977, p. 17). In consideration of the disruptive and itinerant arrival of skin conditions, it may be reasonable to suggest that narrative interviewing might help participant contributors to negotiate the “asymmetry” between their past and present identities. Viewing the narrative interview process through the lens of Narrative Therapy (White, 1988) helped me to locate the interview as a dialogic, liminal space for the “re-authoring” or “re-storying” of identity (Turner, 1982). Accordingly, I audited how my research questions may have co-authored, framed, or shaped participant contributors’ personal narratives and understandings.

In tandem with narrative’s interpretive import, greater still is the indeterminacy and instability of its enunciation. Aligned with grounded theory’s pursuit of meaning over accuracy, narrative organically engages the subjective perceptions of human beings situated in location and time. No matter how comprehensive or ossified the narrative response, however, “in the realm of narrative, we are always and inevitably reading for meaning, knowing all the while that our accounts are destined to remain provisional” (DeFina, 2015, p. 29). This indeterminate feature of narrative enables multiple, shifting meanings to co-inhabit a participant’s story. By adopting a narrative vantage point that aimed to position the participant contributor as the central author of their story, this study aspired to aid participants in undoing the obstinacy of stigmatization, uncovering not only deeper insight into the ambiguities and ambivalences of lived experiences, but also enriched self-awareness loosened through the slippage between “now” and “then.”

Participants

The participant contributors to this study self-identified as meeting the following three criteria: being over the age of 18; having a skin condition and/or other marking(s) of the skin; having one or more body modifications. Additionally, all participants were asked to complete a photo and video release document that granted me permission to create a multimedia digital storytelling presentation to publicly communicate the findings in the future. Each woman who spoke with me met these criteria and voluntarily elected to participate in the project. No compensation was provided for taking part in this study.

During the participant recruitment phase of this project, I employed a snowball sampling method to reach individuals willing to talk about their markings of the skin and experience of stigmatization. In doing so, I sent emails and social media posts to my network of family and friends, many of whom work as professional tattoo artists. This network then forwarded the recruitment flyer to their contacts. Additionally, I sent emails to tattoo shops and artists across the country to pass along the flyer to their clientele. Since this recruitment method yielded fewer participant volunteers than anticipated, I posted about the study on Facebook groups focused on the topics of skin conditions and body modification. Several moderators of these Facebook groups then volunteered to share the project flyer with their personal contacts. In total, 24 people responded to these recruitment methods, 15 were eligible to participate, and 7 completed an interview.

While experiential nuances of each type of skin condition may exist, this study analyzed the experiences of seven individuals who each had one of five different skin conditions: (1) vitiligo, a skin condition that results in hypopigmentation or loss of pigment across the body; (2) alopecia areata, a skin condition associated with hair loss on the scalp and other areas of the body; (3) psoriasis, a skin condition that causes bumpy, scaly areas of irritation and redness; (4) cystic acne, a skin condition resulting in large, painful cysts and pus-filled lesions; and (5) eczema, a skin condition resulting in dry, flaky areas accompanied by itchiness and discoloration. The characteristics and demographics of the contributors to this study represent a diverse variety of social experiences (see Appendix A for a table outlining the range of conditions experienced by contributors, as well as other demographic factors). In addition to having a skin condition, all contributors reported having a body modification including, but not limited to: tattoos, piercings, and/or plastic surgery.

Preceding the interview sessions, contributors were given the option to report gender, race, ethnicity, nationality, religion, and age. The ages of the women who took part in this project ranged from 20 to 48 years, with the highest concentration of participants between 28 and 31 years old. The racial/ethnic identifications of participants included White/Caucasian, African-American, and Mexican-American. All seven of the participants were female. Three participants reported having vitiligo; one participant reported having alopecia; one participant reported having psoriasis; one participant reported having cystic acne; and one participant reported having eczema. Among the seven contributors, six reported having a tattoo; five reported having piercings; and one reported having plastic surgery (see Appendix A for a table outlining this demographic information).

Data Collection

In order to collect the data for this project, I conducted private, semi-structured interviews scaffolded by primary research questions and follow-up prompts (see Appendix B). Each interview comprised approximately one hour of conversation. The complete duration of interview time analyzed for this study was approximately 8.5 hours. Each interview was conducted either as a video chat or phone call, allowing participants to conduct the interview in a private location of their choosing. In order to ensure privacy of the contributors, I conducted my end of the video chats and phone calls at my home and in private locations on the East Tennessee State University campus.

In alignment with grounded theory (Charmaz 2014), my interview questions evolved throughout the study in order to attend to emergent themes and intersectional considerations. As my recruitment efforts unfolded, I discovered that all of the contributors to this study self-identified as women. The interview sessions with these women displayed the significance of their gender identity in their personal life experiences. Acknowledging this disparity between my participants and my own gender identity as a man, I began to include an interview question that asked my contributors to reflect upon the influence of gender in their processes of identity construction (see Appendix B). Similarly, two of the women in this study identified as persons of color. In reflecting upon my own social location as a white man, I also included a question exploring the relationship of racial identity to the experience of having a skin condition and body modifications. While unplanned at the outset of the interview process, these intersectional considerations developed organically through attending to my own social position as a researcher in juxtaposition with the lived experiences of my contributors.

I completed the audio recordings with two recorders and then uploaded and transcribed the digital files. After the process of transcription, I listened again to each interview to ensure the accuracy of each transcript. I safeguarded contributor confidentiality by both using pseudonyms and eliminating direct identifiers from the transcripts. This study was approved by East Tennessee State University's Institutional Review Board.

Life Story Interviews

The interview guide for this study was influenced by the "life story interview" model advanced by McAdams (2001) (see Appendix B). Life story interviews often prompt people to investigate the meaning of lived experiences by incorporating them into their views of their life and self (McAdams & Bowman, 2001). Scenes from life stories can animate a participant's "narrative identity," defined by McAdams as "a person's internalized and evolving life story, integrating the reconstructed past and imagined future to provide life with some degree of unity and purpose" (Mcadams & McLean, 2013, p. 233). This study adopts McAdams' (2001) approach to life story interviews by engaging participants to narrate chapters in their life, guided by a semi-structured series of follow-up prompts that explore high points, low points, turning points, vivid memories, wisdom events, future scripts, challenges, personal ideologies, life themes, and/or reflections as applicable. Participants were asked to reflect on how their skin conditions and body modifications have impacted their social relationships, self-presentation, and management of impressions. This narrative approach aimed to address how individuals situated themselves as social actors enjambed in various interpersonal contexts.

“Shadow Stories”

When conducting, transcribing, and coding my interviews, I attempted to identify “shadow stories,” as described by de Medeiros and Rubinstein (2015). This term refers to “the untold stories—the silence, gaps, and omissions” of a narrative that “lie just below the surface of what is said or written.” In the process of uncovering these “shadow stories,” my follow-up and probing questions addressed omitted details and alternate, potentially competing narratives. This research orientation directs a concern for what Goffman (1961) might call “unique outcomes” or exceptions to the problem’s primary narrative (pp. 321-328). I encouraged participant contributors to identify the more neglected events of their personal stories and to weave these unique outcomes into alternative story lines or “unique accounts” by asking divergent follow-up questions. For example, when a contributor enumerated a list of instances when she had been stigmatized by strangers, I asked her to consider times when strangers made her feel positive about her skin condition. Additionally, I attempted to ask follow-up questions that could elicit “unique outcomes” whenever I heard participants described life events using absolute terms such as “never” and “always.” As an interviewer, I worked to generate questions intended to “produce, locate, and resurrect alternative (and preferred) stories” that helped support participant contributors to “more fully inhabit their lives and their relationships” (Madigan, 2016).

My semi-structured interview guide incorporated a blend of both the Patton and Spradley Models, as cited by Madison (2012, pp. 29-32). By integrating feeling, experience, emotion, opinion, and advice questions from the Patton and Spradley Models, I aimed to provide opportunities for participants of various dispositions to narrate and verbally author life experiences. In developing my interview question guide, I considered that a variety of question types might better reveal “stories that lived outside the dominant problem stories being told” both about participant contributors and by participant contributors themselves. To this end, I began incorporating questions about the contributors' intersectional identities, exploring the influence of factors such as gender and race. Additionally, I reflected upon my position of power as a male researcher with female participants and exercised caution when probing for alternative plots. Acknowledging how my focus on "unique outcomes" could have potentially challenged or confronted participant reports, I began my interviews by disclosing that I have vitiligo and tattoos. In doing so, I hoped to create a safe, welcoming environment for my participants to plumb and re-author sensitive life experiences.

Data Analysis

After each interview, I transcribed the audio recordings verbatim, totaling 227 pages single-spaced, using both a secure transcription software called Descript and an audio production program named GarageBand. Once each interview file had been run through the transcription software, I then re-listened to the audio at half-speed to ensure the accuracy of the transcript. In order to protect contributor confidentiality, I assigned pseudonyms to each interview participant and altered all identifying information. No identifying details were included in my data analysis or findings.

Analysis of the data utilized a multi-phasic grounded theory approach as described by Charmaz (2014). During the transcription process, I noted the time stamps of salient themes as they emerged from the data. Following the transcription process, I simultaneously listened to each interview and read the transcript in order to better associate the narrative identity of the participant with the written material (McAdams, 2006). While both explicit and tacit expressions may elicit one's narrative identity, McAdams (2006) discussed the significance of themes of redemption and contamination amongst individuals experiencing health challenges. Accordingly, I adopted McAdams' focus on narratives of redemption and contamination throughout my coding process. In redemptive narratives, a problematic event or an emotionally negative experience is reinterpreted as having a positive outcome. Conversely, contamination narratives recount positive experiences that are perceived to be spoiled by a negative outcome (McAdams, Reynolds, Lewis, Patten & Bowman, 2001). These narrative sequences established a frame for me to code and analyze participant reports, exploring the social dimensions of skin conditions and body modifications.

Adopting this thematic lens, I then conducted “initial” open coding, writing analytic memos as I read, and reread the transcripts (Charmaz, 2014, p. 109). Throughout the coding process, I examined *in vivo* terms the women employed to describe their experiences (Saldaña, 2016, pp. 77-80). This first phase of initial coding challenged me to identify key details and affective aspects of contributor responses. In doing so, I utilized descriptive, gerund, and versus coding as applicable to the interviews (Saldaña, 2016, pp. 67-211). In the second phase of focused coding, I selected and compared relevant codes across the interviews to constellate correspondent images and themes (Bauer & Murray, 2018). I then related these emergent themes back to central *in vivo* terms to establish more general categories for organizing the data.

In keeping with McAdams’ (2001) approach to life story interviews, I then reviewed the data a separate time with a wider attention to life chapters, key scenes in the story, future scripts, challenges, personal ideologies, life themes, and individual reflections. In doing so, I sought to outline themes of contamination, redemption, and recovery. By comparing my own initial and focused codes gathered from the interviews against these narrative sequences from McAdams’ (2001) life story interview model, I sought to situate codes not only thematically, but also in consideration of their narrative functions within the participants’ reported life stories. This narrative orientation further informed my processes of self-reflexivity.

This attention to personal narratives and self-characterization established “agency” as an overarching theme throughout the findings. In some scenarios, the women who talked with me presented themselves as active agents in managing stigmatization and determining their own life outcomes. In other circumstances, however, they portrayed themselves as more passive figures. Accordingly, my analysis then explored the various contexts that compromised contributors’ agency alongside the various strategies that they employed to protect, restore, and ensure the expression of agency in their lives. As a result, three main contexts arose from the data. The first context explored how contributors navigated the diverse medical dilemmas brought on by their skin conditions. The second context displayed how affected individuals conceptualized and reclaimed ownership over their own bodies. The third context examined the frameworks and strategies they implemented to gain agency over their social identities.

Due to the range of skin conditions and body modification practices represented amongst contributors, the data in this study often displayed lack of uniformity in reported experiences. Since each of the contributors underwent significantly different life experiences, coding the transcripts in this study presented analytical challenges. Only three of the seven participants had the same skin condition, while the study also explored an array of tattoos, body piercings, and plastic surgery modifications. Although these practices may be nominally categorized as a collection of “body modification practices,” the data displayed significant differences in their personal functions. While these idiosyncrasies offered interesting insights, my analysis of the data sought to organize the emergent themes under commonly shared categories. Attending to the breadth of contributors’ life experiences, I developed codes that strived to contain ambivalent and contradictory reported experiences. In order to counteract this generalizing research constraint, the narrative framework of this project seeks to attend to the reported nuances and differences between contributors.

Self-Reflexivity

Self-reflexivity constituted an integral aspect of my data collection and analysis. I disclosed to contributors early in the interviews that my motivation to pursue this study derived from my personal experience of having both vitiligo and body modifications (Hazen, 2003). In this spirit of reciprocity, I employed “writing as a method of inquiry” by journaling my own responses to each of my own interview questions (Richardson, 2011, p. 959). As I later analyzed and coded the data, I focused on both the thematic prevalence of certain codes and their narrative significance to contributor life stories. Compared against my own journal responses, I then reflected not only on my identification with the emergent codes from participants, but also upon my connection to the plot elements of each of the women’s life stories. Examining narrative sequences of redemption and contamination further accentuated my own process of making meaning from my own skin condition and body modifications. This became most apparent through the process of developing my own illness narrative where I reflected upon the enjambment of my personal story within the research process, exploring themes of visibility, disclosure, and narrative embodiment. By expressing and recording my own life experiences as both an interviewer and “interviewee,” I attempted to prevent my own personal narrative from dominating the analytical process.

In comparing my own experiences alongside those shared by my contributors, I adapted and changed my interview questions to better reflect the intersectional dimensions of living with a skin condition and body modifications. When initially designing the study, I had anticipated that multiple gender identities might be represented among the contributors in this study. As my recruitment process developed, however, the contributors to this project all self-identified as women and some self-identified as women of color. That said, intersectional factors appeared throughout the interview sessions and I attempted to attend to these aspects of contributor life experiences as they arose in conversation. In reflecting further upon my own experiences as a cis-gendered white man, I decided to include questions that explored the influence of gender and race in contributor life experiences. Examining my own journey as a straight white cis-gendered male helped me to contrast my own biases as a researcher against the experiences of my contributors, revealing intersectional nuances to illness, body modification, and appearance-related stigma.

Additionally, I engaged in self-reflexive journaling to examine the personal experiences and beliefs underpinning my research inquiries. I explored my predispositions and emotional responses to the interviews and the participants. In this study, I had to consistently observe and tame my projections of my personal experience within the reports of my participants (Bauer & Murray, 2018). Subsequently, this self-reflexive journal both complemented and complicated the process of analyzing the interview transcripts. My journaling process illuminated how my role as the researcher positioned me in a place of optical power, interrogating my subjective and selective process of presenting this study’s findings. Rather than feign objectivity, I instead decided to acknowledge my own authorship not only in my own personal narrative, but my selection of segments from participant life stories as I strove to co-construct a “meaningful” narrative.

In the following chapter, I detail the primary findings that these methodological processes produced. As I coded and categorized the data, I reflected upon my situatedness in the study. In this sense, I audited my inclination to project aspects of my own experience on to contributor reports. While some of the data misaligned with the central theme of “agency” and “agentic strategies,” this broad frame helped to position and organize the data with an attention towards identity construction. Although the problem-solution structure of the following chapter presupposes that skin conditions are essentially negative, this organizational pattern highlights the utility of body modifications in assisting affected individuals to reclaim their agency across a range of personal and relational domains.

Chapter 4. Findings

In exploring the relationships between body modifications, skin conditions, and the construction of identity, this study circumambulated the continually negotiated tensions between feelings of powerlessness and agency. Although contributors to this study often figured themselves within a diffuse matrix of challenges, their narratives featured contextually contingent strategies that promoted agency in various personal and relational domains. Advancing previous scholarship surrounding skin conditions and body modification practices, this study constellates not only a web of disempowering factors that influence affected individuals' lives, but also the strategies they employ to embolden and bolster self-determination and resiliency (Atkinson, 2004; Shih, 2004). Consistent with grounded theory, I was surprised that contributors desired to share deeply intimate details about navigating their relationships to treatment, their bodies, and their social identities. While this project initially sought to uncover the de-stigmatization strategies that individuals with skin conditions might employ, the interviews with each of this study's seven women cast considerable attention to the matrix of challenges they individually confronted. In presenting these challenges in the sections that follow, I hope to express the application and import of such strategies as they featured in contributors' lives. Considering the significance of this interplay in contributor life experiences, I have chosen to present this study's findings through a problem-solution organizational pattern that outlines the dilemmas they faced alongside the diverse strategies they developed to amplify a sense of agency and empowerment.

Reclaiming Medical Agency

Developing a skin condition can induce feelings of diminished control over one's body. Additionally, the available courses of treatment for skin-related illnesses may further exacerbate this felt lack of agency. Contributors to this study shared narratives that predominantly featured their complicated medical journeys and the processes by which they felt detached from and disenchanted with treatment. The compulsory nature of skin conditions in tandem with the dearth of medical options render many affected individuals helpless in effecting bodily changes. As a response to feeling powerless, the women who participated in this study developed and employed a range of adaptive coping strategies that promoted feelings of agency in their pathways towards healing.

Medical Exhaustion

Complicated by the felt lack of agency many affected individuals experience from the appearance of their conditions, most medical interventions provide little to no relief. Each of the women in this study recounted a series of ineffective procedures, prescription medications, over-the-counter treatments, and medical interventions that failed to permanently resolve their skin conditions. Throughout the course of these various treatments, individuals may subject themselves to a series of side effects not typically listed on treatment labels and procedure consent forms. Amplifying feelings of powerlessness, contributors discussed undergoing a matrix of psychological and physical trials for the sake of treatment.

On a fundamental level, the onset and trajectory of skin conditions can usurp one’s control over their own bodily processes. All of the contributors in this study reported feeling a lack of agency because of the appearance and treatment of their skin conditions. As one of my contributors, Jacqui noted, “the psoriasis is not my choice.” Illnesses are indeed rarely self-elected. Individuals with permanent, incurable skin conditions, however, may increasingly struggle to position themselves as active agents in their own embodied experiences. For contributors like Lucia, the arrival of a skin condition may derive from genetic factors. This inborn, hereditary aspect of some skin conditions can challenge the effectiveness of many medical interventions and quash hope for improvement. Other contributors, however, grappled with inconclusive explanations for the arrival of their skin conditions. Stephanie described her inability to control her alopecia, remarking, “It just kind of comes and goes whenever it wants to.” She continued to explain:

> “My alopecia is never gonna go away . . . It's always going to be here with me. It's just a matter of if it's gonna have an episode or not . . . or I can never have it again, just so this might be my last time I'm having alopecia. I don't really know.”

The unpredictable and unyielding temperaments of many skin conditions disempower and discourage individuals from accessing and enacting effectual medical care.

While many skin conditions periodically recede and reappear, the individual experiencing the condition may undergo an unremitting process of receiving and responding to treatment. Stephanie expanded on her reaction to the appearance of her alopecia:

> “It affects me differently every time . . . Like the first time I got it, I was super self-conscious about it . . . The second time I got it, I was super, super honest and open about it. Third time's super honest and open about it. Fourth time, I'm like a little sketchy and not really sure how I'm supposed to feel . . . I’m kind of always in the healing process.”

The itinerant presentation and episodic dormancy of their skin conditions often compelled contributors to vigilantly maintain their wellbeing. Lauren also discussed her eczema’s uncompromising demands, noting, “When you stop taking like good personal care of yourself because you’ve like shifted your focus to other things, then I can like see it kind of coming back in.” Charged with continually attending to their health, the women in this study repeatedly reported feeling disempowered and fatigued.

As affected individuals explore treatment options, they may encounter a range of unforeseen psychological challenges. The medical process, as an amelioratory, corrective undertaking, often hinges on hope. Medical providers and patients alike aim for treatments to result in a positive outcome. When these promises and expectations remain unfulfilled, however, patients can feel hopeless and powerless to improve their wellbeing. This study affirms that multiple trials of repeated, sustained treatments can threaten a patient's optimism. Stephanie discussed this challenge in her medical journey to regrow her hair from alopecia: "I tried Rogaine; I tread biotin; I tried every pill under the sea; I tried managing my stress; I tried creams; I tried laser therapy; I tried everything and nothing would work." Later in the interview, she detailed a remaining treatment she had refused, noting, "it'd be over 50 injections into my head." With each newly failed treatment that Stephanie underwent, she faced a dilemma about when to discontinue her search for a cure, and, ultimately, when to surrender hope.

Similarly describing the psychological endurance required to treat her condition, Lauren stated that her eczema appeared to be "very resistant to a lot of medication." She then outlined a process of medical "trial and error" in which she "had to try a bunch" of different medications to determine the correct treatment and dosage for her eczema. She added that her eczema episodes often required an idiosyncratic treatment protocol: "If I have a bad flare, I have to take like topical steroid medication. Sometimes antibiotics . . . it gets so bad that like, I'll start to bleed or puss through." As the term "trial and error" implies, exploring medical options regularly results in failure, inhibiting the individual from altering physical outcomes.

Aside from more formal medical interventions, navigating the safe and effective use of over-the-counter treatments may further add to the exhaustion that affected individuals experience. Sophie described an “error” experience with using sunscreen as a preventative treatment:

> It's just really difficult because you’ve got to apply sunscreen all the time and it's, it's just annoying. As soon as you forget it, where you were in the water and you don't apply it [afterwards] right away. Again, you burn so bad . . . I had burned just like one month ago and [it was so] bad that I have a scar now here.

For someone with vitiligo like Sophie, sunburn can cause permanent damage to the skin. In exchange for the “trial” of swimming without immediately re-applying sunscreen, Sophie experienced an “error” that traumatized her skin and irreversibly changed her appearance. While medical interventions may prove ineffective for many skin conditions, over-the-counter treatments may also require exceedingly vigilant observation and persistently frequent re-administration. The demanding process of maintenance and emotionally upheaving course of treatment can strain a patient’s psychological stability. If affected individuals do collect the mental energy to undergo treatment, however, their physical bodies may respond unfavorably.

Prolonged and rotating medical treatments can physically harm patients as they adjust to new medications and acquaint themselves to new treatment regimens. Lucia commented, “I did Accutane, which was horrible. It made my eyelids crack and bleed, so I don’t recommend Accutane to anybody.” Echoing this reflection on physical harm, Stephanie said that her hair injections “didn’t do anything” for her except give her “a lumpy head.” In addition to harmful physical side effects, the process of migrating between medical programs can further exacerbate the skin conditions that such protocols intend to remedy. Stephanie remarked, “If I switch up my medication, it kind of triggers [the eczema].” Likewise, contributors identified risks associated with failure to educate oneself about over-the-counter treatments. Lucia talked about accidentally misusing a particular face wash to address her acne:

> “I actually bleached off all my freckles. That was an accident. I used, uhm, I used face wash with bleach. Oh, I didn’t know it had bleach, so my, my skin became significantly whiter . . . It was an accidental bleaching of my face.”

The physical toll of exploring new interventions impeded contributors from feeling in control of their medical care and bodily experience. While medical treatments can impose mental and physical taxes on an affected individual’s resiliency, medical interventions may also present parallel social obstacles.

In conjunction with the mental and physical challenges of treatment, affected individuals may confront added financial and relational complications in seeking and receiving care. While treatment may exact a significant toll on an affected individual’s life, the medical process also demands inhibitory financial costs. Compounding these stressors, affected individuals may also confront difficult relational dynamics as a patient within the medical care exchange. While outside the scope of this study, this research appears to affirm previous research indicating that these financial and relational barriers may be further troubled by intersectional facets of identity (Kielb, E., Rhyan, C., & Lee, J., 2017; McCarthy, 2014).

When affected individuals opt for medical treatment, they often confront the healthcare system’s high cost of entry. The women who participated in this study reported that financial concerns operated as barriers to seeking and receiving medical attention. Sophie illustrated how financial pressures can aggravate feelings of powerlessness: “If you do a transplant, that costs a lot of money. Creams, if you do it consistently, costs a lot of money . . . This is something that is out of your control.” Consequently, contributors debated the costs and benefits of receiving medical care. “It’s something that you have to keep up consistently,” Lucia explained; “I just right now cannot justify to get an over $1,200, kind of a, a pop experience.” She remarked that alternatively, “you kinda just have to now experiment with face washes.” Considering how skin conditions often remain impervious to medical interventions, affected individuals wrestle with the notion that they may not receive a sound return on investment. “I never used anything, really,” Sophie added, “because I did not want to spend money on something that gets my hopes up and then it's not going to work out in the end.” The monetary cost of medical care can structurally prohibit individuals from exerting agency over their skin conditions.

Complicating the financial burdens associated with medical care, contributors shared experiences in which relationships with medical providers deterred them from pursuing treatment. Lucia found that not touching or aggravating her skin was a difficult struggle for her, and that she did not receive support or help from her provider in that struggle. She recounted that the “first thing” her dermatologist would communicate was, “Well, we can’t help you because you pick at your skin. And I’m like, well why am I getting acne to begin with?” Lucia continued to say that she favored receiving treatment in a foreign country because the “language barrier” made her feel safe from judgment: “They just jumped straight into treatment . . . I'm sure they probably said something about like picking, but they didn't address it to me.” She felt that this offered her the support, the “psychological aspect,” that she felt she needed. Although relationships with medical providers may offer positive outcomes, as Lauren described with her eczema, the interpersonal dynamics of treatment may also complicate affected individuals’ processes of help-seeking. For Lucia, the confluence of financial concerns alongside troubled relationships with doctors dissuaded her from treating her cystic acne. She noted,

> I don’t want to like totally dismiss every dermatologist in the States, but I just personally have not experienced like a positive … it's a psychological block, that I don't want to go back. Because I'm like, “Oh, it's too expensive and they're going to be rude to me. So, pass.”

Financial hurdles combined with interpersonal challenges disenfranchised Lucia from exercising medical agency.

Affected individuals undergoing medical treatments may experience an array of psychological and physical challenges. On a basic level, the arrival of an illness often initiates a sense of removal of bodily control. Medically addressing one’s skin condition can further perpetuate this felt lack of agency. Individuals with skin conditions often shoulder a psychologically demanding medical process filled with repeatedly dashed hopes. In order to continue receiving treatments, patients must complement their psychological endurance with physical wherewithal. As affected individuals contemplate their medical options, they reckon with financial and relational hurdles. This web of challenges exacerbates the exhaustion that affected individuals already experience. Presented with this matrix of barriers to seeking and receiving medical care, affected individuals may feel a sense of compromised agency.

Concomitant Health Issues

In tension with medical exhaustion and the various barriers associated with medical care, affected individuals may also develop additional health problems beyond their skin conditions. While many skin conditions can appear as self-contained illnesses, they may also be accompanied by a multitude of other physical and mental health-related issues (Hunt & McHale, 2005; Safaeian et al., 2013). The women in this study reported feeling distress about the looming threat of secondary and tertiary diagnoses. Consistent with previous research, this study also illustrates the significant psychological repercussions of skin conditions (Hunt, N. & McHale, S., 2005; Nardi et al., 2005). Since skin conditions generally develop in opposition to an affected individual's will, contributors discussed feeling forced to surrender to their condition's dominion over their bodies. These concomitant conditions further disempower affected individuals from exerting agency over their bodies and effecting positive changes in their wellbeing.

Each of the skin conditions explored in this study can potentially present a collection of accompanying medical complications. The majority of contributors asserted that their skin conditions may derive from underlying "autoimmune illnesses." This contested and elusive medical term refers to a category of health conditions characterized by the biomedical model as a series of attacks that the body inflicts upon itself (Selgrade et al., 1999). The biomedical model contends that when an individual receives one autoimmune diagnosis, they are disposed to acquire more. Reflecting upon this health threat, the women reported feeling worried that they might develop additional autoimmune conditions. Although some contributors rebuked the validity of "autoimmunity" as a medical concept, they nonetheless felt threatened by the potentiality of receiving multiple diagnoses. Jacqui reflected on the gravity of receiving an autoimmune diagnosis coupled with her skin condition diagnosis:

> "I also have asthma . . . they go hand in hand. Usually if you have one autoimmune disorder, you have more than one . . . So, psoriatic arthritis is what's next on my, um, my list of 'Oh, happy days.' And I feel it in my joints . . . especially on my elbows . . . So, I'm not looking forward to that. So, I'm trying to, you know, that's a condition that, it's going to debilitate my ability, you know, like my motor function. I don't know . . . I don't know how that's going to play out in my future . . . So, it's kind of a worrisome thing."

Jacqui's increased likelihood for acquiring additional "autoimmune illnesses" subjugates her under the condition's corporeal authority. Alongside feeling dominated by her psoriasis, Jacqui's inability to prevent emergent "autoimmune illnesses" further obstructs her agency over her body and physical wellbeing.

Physical health concerns may problematize the experience of having a skin condition, but concomitant mental health issues may more significantly impact an individual's sensation and expression of control. This study corroborates previous research that exhibited the psychological effects of skin conditions (Hunt & McHale, 2005; Lucas, 1961; Nardi et al., 2005; Obradors et al., 2016). While some research posits that skin conditions develop as psychosomatic disorders, this study does not seek to explain the origins of skin conditions, but rather, aims to sketch their aftermath as reported by affected individuals (Picardi et al., 2005). Contributors rejected the notion that their conditions were merely cosmetic, contending that they also produced profound psychological distress.

Discussing the mental health challenges associated with alopecia, Stephanie stated that for her: "It's more of an emotional disease than it is a physical disease." Nearly all of the women shared similar experiences, contrasting the relatively benign physical effects of skin changes against the significant emotional turmoil provoked by their conditions. Shortly after the arrival of her vitiligo, Natasha also said, she underwent a process of "just belittling myself and just hating my skin and just self-pitying and then it was just horrible." As individuals experience severe psychological disruption, they may also develop concurrent mental health diagnoses. For example, Jacqui emphasized her skin condition's relationship to her depression and suicide attempt. Likewise, Lauren highlighted how the lack of control over her skin condition may have stimulated her development of concurrent mental health disorders:

> "When I was younger, like from a very young age, had like issues with like disorders and body image . . . And I feel like that also was, I guess in relation to, uhm, you know, wanting to be able to control a little bit more of what was going on . . . So, like figuring out how the management, and it effectively took a long time . . . and I feel like it always felt like very out of my control and like very embarrassing at that young age."

For Lauren, lack of agency over her skin condition impacted, she said, any "interest in controlling what I feasibly could about my appearance," thereby amplifying discordant disorders and body image issues. As affected individuals encounter emergent mental health issues alongside their skin conditions, they experienced a lack of agency in determining their wellness outcomes. Meanwhile, this compromised agency can potentially give rise to new psychological challenges. Consequently, contributors reported feeling disempowered in managing their mental health.

While physical skin conditions may provoke psychological dis-regulation, they are simultaneously induced and aggravated by stress. Describing how the onset of her vitiligo generated emotional tension, Natasha stated, "So of course [the onset of the condition] builds up more stress . . . And it just manifests into little spots. And I did not know that stressing actually makes it worse." This linkage of correlated stress responses also underpinned Jacqui's claim: "The more I got sick in my head, the more I got sick in my body." Multiple contributors envisioned the interrelationship between both the *stress-induced* and *stress-inducing* dimensions of skin conditions as a "cyclical" process. Kayla asserted, "When I first saw [the visible changes] . . . it stressed me out that it was spreading. So, it was just like a never-ending cycle of stress." This feedback loop of stress fatigues affected individuals, reducing their ability to alleviate their skin conditions and resolve psychological challenges.

The dual-directional cycle of stress associated with skin conditions may engender serious consequences. Kayla mentioned how the stress from her vitiligo spoiled her attempted medical treatments:

> “I started light therapy and I got a lot of color back. Not all of it, by any means, but I got a lot of color back. And then after I went through that [stressful] year, I lost like most of what I had gotten back . . . like very quickly . . . I noticed when it, when I started losing it because of stress.”

Kayla’s vitiligo was aggravated by the very same stress it created, further interfering with her attempts towards medical progress. Consequently, Kayla experienced a lack of agency in her ability to effectively employ medical interventions in her process of treatment.

The stressors of skin conditions and their subsequent physical complications can thwart medical interventions. After losing control of her skin condition, Lucia perseverated on the issue by compulsively picking at her skin. She described the this behavior as a “nervous tick” that she felt unable to stop:

> “You don't realize how often you touch your face. Like if you rubbed ink on your hands and saw how many fingerprints you have on your face, it's absurd . . . I've done that once before just to see how many times I touched my face in a day . . . I did it on a day off and I was like, I have like a hundred thumbprints, fingerprints all over my face.”

From Lucia’s perspective, obsessively picking at her skin resulted from the feeling of being unable to control her cystic acne. Unfortunately, this behavior further prevented her from resolving her condition. Lucia’s doctors told her that her compulsive picking had worsened the issue and they refused to treat her until she stopped touching her face. This “nervous tick” not only jeopardized Lucia’s access to medical care, but also actively undermined her healing process. She discussed how this “nervous tendency” exacerbated her cystic acne: “I can always tell like when it’s going to be really bad. It’s ‘cause I've just been like poking at my little cysts and I'm like, ‘Oh, okay. Now it's spread.’” Lucia’s cystic acne spurred associated mental health problems that bound her in a cycle of stress and compromised her ability to influence observable outcomes in her skin.

Individuals with markings of the skin must navigate a variety of health issues and stressors that can physically and mentally inhibit their medical treatment. The associated health problems of skin conditions may undo the medical progress affected individuals achieve. Meanwhile, problematic stress responses may complicate one’s ability to receive treatment in the first place. Since skin conditions can give rise to emotional distress, they may necessitate mental health support beyond physical interventions. These additional mental health issues further challenge affected individuals from making positive changes to their state health. All of the contributors in this study discussed their disenchantment with the biomedical course of treatment, citing the stubbornness of their conditions and the ineffectiveness of treatments.

Navigating Skepticism

As Arianayagam & Ryan (2016) showed, the biomedical field has failed to provide fully effective therapies and explanations for many skin conditions. Additionally, a range of medical perspectives offer contradictory arguments in favor of or against various forms of treatment. Considering the significant physical and psychological challenges associated with biomedical treatments, many contributors described feeling disenchanted with their available medical options. In exposing themselves to new treatments, contributors waded through complex medical terminology to determine the efficacy of prospective treatments and evaluate whether such treatments would cause them physical harm. Since contributors repeatedly underwent ineffective and potentially dangerous medical protocols, they often grappled with the notion that future treatments would work for them. Each of the women described feeling conflicted about hoping that unexplored treatment options would resolve their skin conditions. Given the degree of mental energy individuals with skin conditions must exert coupled with the biomedical model's inability to produce a lasting cure, contributors reported that they had repositioned themselves as primary agents in prospective healing regimens and as central decision-makers concerning potential medical treatments.

In tandem with medical fatigue, barriers to care, and concomitant health issues, every contributor in this study discussed feeling skeptical about the safety and efficacy of medical approaches. All of the women discussed their reservations about exploring future medical options. Expressing discomfort with the side effects of her dermatologist's suggested treatments, Sophie commented: "They say there are some creams or lotions that you could use, but it's not 100% safe." Similarly, Danielle weighed the possibility that bleaching her skin could counter-intuitively intensify her vitiligo: "It wouldn't all blend anyway, so I would just . . . lose even more color, and like, have it still be uneven." Distrust in medical interventions further complicated contributors' processes of medically addressing their skin conditions, amplifying feelings of powerlessness.

As affected individuals grapple with available options in the present, they must also negotiate decisions about medicine's future frontiers. The contributors to this study unanimously reported feeling ambivalent about trying newly developed treatments. Natasha contemplated how she would feel if the medical establishment presented a "cure" for her vitiligo. She commented, "I also have this fear that if I take this damn cure, what if it makes it worse? What if it gives me cancer? I'm just going to go with the fucking flow already." Natasha's frustration illustrates the tension that affected individuals confront when presented with new medical choices. While Natasha felt drawn to the possibility of ameliorating her vitiligo, she simultaneously acknowledged that her safest option may have been to “let nature do its work.”

Paralleling this dilemma, Lauren described her mixed feelings when being “recruited” and “asked to participate in different clinical trials.” She noted, “I would like need to have daily injections to try and uh, eradicate it, um, which I never participated in just because of the risks.” Although Lauren reported feeling concerned about the potential health complications associated with these clinical trials, she displayed ambivalence about the development of future medications. She continued,

> “I hope that they're working on developing a drug that would be similar to Accutane . . . It's very dangerous . . . a lot of side effects, for a certain period of time, but then like, allegedly you would never have a flare up.”

Lauren’s conflicted feelings about future medical advancements display the state of suspended disbelief in which many affected individuals are forced to dwell. On one hand, individuals with skin conditions must discern whether specific treatments will harm them or promote their wellbeing. On the other hand, their optimism can operate as a vulnerability that makes them more easily recruited for the purposes of broader scientific research and product development. Held between each of these two hands, however, remains the hope expressed by each contributor for the discovery of a lasting, permanent cure. As science and technology present new treatment options, however, affected individuals determining their pathway towards healing must decide how big of a pill their hope can swallow.

In response to the myriad challenges of their medical journeys, many contributors reclaimed their agency by discrediting medical opinions in favor of their own somatically-informed conclusions. Some of the women challenged their doctor's medical explanations for the onset of their conditions. "The dermatologist told me that [the eczema] worsens with the change in the seasonal environment, like a change and the allergens," Lauren reflected, "but I don't know if that's right." Lauren questioned the accuracy of her doctor's explanation for her eczema. In a similar way, Jacqui rejected the notion that pharmaceutical medications were helping her condition: "I don't take prescriptions anymore, so I think that also keeps my psoriasis at bay." By critically selecting and valuing medical advice, contributors re-positioned themselves as the primary care providers for their own bodily experiences. In Jacqui's view, the notion that "doctor knows best" comes secondary to her own subjective bodily understandings. She reflected upon the idea that doctors know more about skin conditions than their patients, claiming, "I don't think that's true . . . I mean, not anymore. There was probably a time that I did, but not now." Jacqui's disenchantment with the medical model reframed her relationship to her body and repositioned her as the locus of control in her own caretaking process.

Extending this internal orientation towards control, contributors revised medical literature and explanations for their skin conditions. They noted the significant influence of their mental health, as well as diet and environmental factors. Jacqui outlined her assessment of her conditions as follows:

> "I would say the flare-ups are probably 10 percent environmental, ya know, like chemicals or external substances . . . Probably, uhm, probably 20 percent of what I eat and what I'm putting in my body . . . And the rest of it is all stress and mental . . . I think it absolutely, 70, at least 70 percent of it deals with where my head is."

While Jacqui provided a detailed explanation for her condition's onset, numerically attributing her psoriasis to a range of causative factors. In contrast, other contributors discussed their process of determining their conditions' inflammatory triggers. Lauren described feeling enmeshed in the exploratory process of better understanding her condition:

> "I don't feel like it's super tied to like stress or diet, but it is like, I'm also in a PhD program . . . And there are times where like when I'm busy and not taking care of myself in that way . . . And I can see, like I can see spots on my body. I thought it's starting to come back and I'm like, 'Wow, that is in your control.'"

In order to cultivate an understanding of her condition's triggers, Lauren self-directedly noted the physical responses brought on by potential triggers to her condition. Although developing a qualitative understanding of one's holistic state of health requires repeated exposure to various inflammatory stimuli, the evolution of this bodily awareness functioned as a strategy of empowerment for contributors seeking to foster a more acute attention to their embodied experience.

The indeterminate origins of many skin conditions provoke affected individuals to continually examine and audit their own health-related behaviors. In doing so, individuals with markings of the skin attempt to calibrate and gauge the influence of their own actions in their condition's development and presentation. Although repositioning oneself as the central agent of healing can intensify a sense of agency, contributors consistently reported feeling exhausted by continually taking personal accountability for their wellbeing. That said, this agency strategy supported individuals to take control of their treatment process, in exchange for other health-related responsibilities and challenges.

Holistic Health and the Interwovenness of Wellness

As a result of their disenchantment with biomedical interventions and their firsthand experiences managing their conditions, the women who spoke with me espoused holistic orientations towards their health. Contributor responses consistently construed their “health” as a matrix of holistic factors including stress management, mental health practices, physical exercise, and diet, among others. In order to address these interrelated aspects of holistic health, the women in this study employed a range of strategies intended to elevate their quality of life. Many contributors elucidated their processes of uncovering physical triggers and promoting their holistic state of health, as Lucia illustrated:

> “I have to go through the works of knowing what really caused it. So, I’m like, ‘Okay, drink more water’ . . . Or, like, ‘Okay, don’t touch my face as much.’ Or the way I will wash my hands more frequently . . . like, don’t touch my phone . . . Or, I sat and, like pseudo-meditated for a while. It's little things that . . . even if it wasn't necessarily clearing out my skin, is still, I think, good for me.”

In consideration of the continual maintenance that skin conditions often require, contributors discussed implementing holistic methods of self-care to support their wellbeing. To this end, body modification operated as both a tool for holistic health promotion and as an aid in managing their skin condition diagnosis. Although addressing one’s holistic health may be an inexhaustible enterprise, the women in this study presented their holistic orientation towards health as an agency-affirming outlook that offered various cumulative benefits.

Intending to improve and maintain their physical state of health, the women who spoke with me adopted and developed a range of holistic practices. Limiting diet, alcohol consumption, drug use, and exposure to chemicals featured as dominant methods by which affected individuals promoted their physical health. In contrast to biomedical approaches towards treatment, individuals displayed a process of *editing out* harmful substances rather than *adding in* new medications and prescriptions. “What do you put in your body?” Jaqui considered, “Whether you’re talking about food or alcohol or illicit drugs or prescriptions . . . all of that has something to do with it.” Expanding on this concept of reducing exposure to aggravating substances, Lauren described her process of managing environmental and chemical sensitivities. She explained that her skin “will react to a lot of unscented things . . . like laundry detergent, new soap, new whatever, can cause a flare.” In order to address this issue, Lauren stated, “I have to have specific products, even like my shower. What I shower with is unscented . . . Everything is.” By controlling her chemical exposure and holistic wellbeing, Lauren exerted her medical agency and fortified her holistic health. While restricting dietary intake and exposure to chemicals appears to impose a series of constraints, the process of controlling physical inputs appeared to assist affected individuals in fostering a sense of agency.

Contributors complemented support for their physical wellbeing by promoting their mental health. Most participants discussed the importance of finding “more or better coping mechanisms when it came to stress and anxiety” (Kayla). These strategies generally require, as Jacqui noted, “diving deep . . . lightening your load, feeling love and joy and being present in the moment.” Contributors developed various contemplative practices to “lighten” their psychic “load.” For example, Lucia discussed her process of journaling to “rationalize a feeling” in managing her obsessive-compulsive disorder (OCD). Meanwhile, for affected individuals like Sophie, the connection between physical and mental wellness functioned as a foundational element of general wellness:

> “With getting stronger and getting physically stronger, you will feel better. You will feel more healthy by losing that extra weight. You want to feel more healthy and that plays with your mental game, too . . . And being mentally healthy, especially mentally healthy, it's gonna go through your whole body.”

Given the nature of skin conditions as both stress-induced and stress-inducing problems, each of the women depicted stress management as a primary feature of their holistic health regimens.

That said, contributors predominantly navigated this process on their own, without medical knowledge of the biological processes involved. Conversely, contributors evaluated their state of health by qualitatively assessing their physical and emotional experiences. Jacqui juxtaposed her intuitive process of gauging her health status with her confessed lack of understanding about cortisol's influence on the body:

> "I don't allow myself to produce so much cortisol. I don't even know if cortisol is a big thing when it comes to the flare-ups . . . When I'm in a high-stress situation or I'm not happy with the things that are going on is when it seems to flare-up more, but I don't know if cortisol is actually directly related to that or not."

As her personal course of treatment unfolded, Jacqui favored her somatic awareness over scientific explanations of bodily functions. Her interview responses, however, demonstrate the precarious status of these somatic understandings. As Jacqui discussed her stress management strategies, she employed Western medical terminology in an attempt to explain her physical stress responses. Despite her usage of biomedical concepts for clarity, Jacqui's prioritization of holistic stress management strategies had largely been generated by her disenchantment with the Western medical model. Consequently, her description displays the tension many affected individuals faced when eschewing medical frameworks while simultaneously implementing medical terminology to justify such self-care decisions.

By holistically supporting their physical and mental wellbeing, contributors strived to reclaim agency in their own healing process. Through limiting their bodily intake, as opposed to supplementing with additional medications or over-the-counter treatments, individuals attended to their physical wellness and reduced exposure to potential triggers. Meanwhile, contributors developed strategies to enrich their mental health and neutralize stress. As interview responses indicated, the process of developing holistic health regimens may require significant trials and errors. The refinement of these practices, however, equipped affected individuals with the ability to fortify their general health while other methods of treatment prove insufficient. Promoting one's holistic health may point to the potential import of body modification as an adjunct healing modality.

Indeed, body modification may operate as a holistic wellness tool that promotes a sense of medical agency among individuals with skin conditions. Contributors discussed a variety of coping and management strategies initiated and facilitated by their body modifications. In some cases, contributors expressed that their body modifications improved their general quality of life, thereby benefitting their skin condition. Other participants, however, selected and designed their body modifications to more explicitly provide permanent reminders and instructions about how to manage their conditions.

It is important to note, however, that injecting the skin with ink, piercing body parts with a gauged needle, and undergoing plastic surgery all cause significant physical stress. As Sophie explained,

> "Getting a tattoo is physical stress. So, I get now more and more white spots in places where my tattoos are. For example, this rose here is fledged full of white spots, but you can see my normal skin around it has nothing."

Although body modification practices may buoy one's mental health, they may also demand their own pound of flesh. Additionally, interview responses suggest that body modifications may not be a panacea or silver bullet for decreased medical control. Nevertheless, each of the contributors in this study presented their body modifications as significantly beneficial for their general wellbeing.

Notably, this study affirms Atkinson's (2004) delineation of tattooing's role in managing and regulating emotions. According to Atkinson (2004), tattoos may provide individuals an opportunity to work through emotional life experiences and events. Several contributors to this study reported that their body modifications encouraged emotional self-regulation and feelings of "calm" (Lauren). Discussing how her rhinoplasty surgery influenced her holistic wellness, Lucia reflected:

> "As a whole, I think having that done and then becoming the person that you become . . . I think it has helped in terms of dealing with stressful situations . . . I just think that I'm much more centered . . . I feel more centered cause I do feel like . . . maybe I'm just more self-aware."

She continued to frame her nose job as an accelerated shortcut towards holistic health: "It's like I see it [nose] and I didn't have to do, practice years of yoga. I just got a nose job . . . So, I jumped the line on that one." As Lucia's experience indicates, body modification supported her healing in ways that other self-care strategies had failed. After receiving news of her grandfather's death, Natasha similarly shared her experience of using her tattoo as an "homage" to mourn him on the day of his passing: "I just know that I needed something . . . to numb the pain and it felt good." In this sense, body modifications supported contributors' holistic wellbeing by assisting them in regulating and managing moments of emotional intensity.

While body modifications may bolster one's emotional self-regulation, they may also facilitate individuals in expressing and sharing sexual intimacy. Although only one contributor in this study discussed the sexual benefits of their body modification, Jacqui's personal narrative displayed a potential “shadow story” uncommonly discussed in popular discourses surrounding body modification (DeMedeiros & Rubinstein, 2015). Jacqui shared that her genital piercing had enabled her to orgasm as a young woman after severe sexual trauma in her childhood. She noted,

> “When it comes to the piercing, especially the clitoral one, uhm I, I’m a much happier human with that in my life. So, yeah, and I think being a happier human, being able to have an orgasm, uhm, and release that oxytocin . . . I’m a happier human because of it.”

Jacqui’s piercing allowed her to “experience sex in a different way on different levels,” promoting her embodied sexual expression. “So, yeah, again its cyclical,” she continued, “Being able to enjoy sex and have it be a fulfilling and rewarding experience and gratifying and satisfying . . . I think all of that plays into my skin condition.” By enriching her general wellbeing through sexual stimulation, Jacqui’s genital piercing bolstered and nourished the management of her psoriasis. She jokingly remarked, “I’d love to be buried with my legs wide open . . . Open casket, here ya go! I recommend this for everybody.” Despite her humorous tone, Jacqui’s comedic statements reveal the extent to which her genital piercing had positively impacted her life. When confronted with compromised medical agency and significant sexual trauma, body modification offered Jacqui the ability to reclaim her bodily agency and experience sexual enjoyment. In doing so, she simultaneously cultivated her general wellbeing, processed trauma, and expressed her sexual drives.

Body modifications may significantly aid individuals with skin conditions in nourishing their holistic health. By compartmentalizing and transfiguring intense emotions, tattoos can permit individuals to neutralize enervating life experiences and make sense of challenging mental states, such as grief. Meanwhile, body piercings may elevate sexual pleasure and assist affected individuals in working through sexual blocks. Contributor reports suggest that body modifications can rejuvenate one’s quality of life and invigorate one’s sense of holistic wellbeing. As a result, body modification can magnify a sense of agency, adorning affected individuals with pathways towards increased happiness. In concert with enhancing holistic health, body modifications may enrich and give meaning to the process of managing a skin condition.

Complementary to body modification’s holistic benefits, tattooing also allows affected individuals to inscribe personal notes and reminders about the management of their conditions. While only two of the seven contributors in this study discussed this inscriptive function of tattooing, their personal narratives provide significant insight into the process of meaning-making that affected individuals may undergo as they reclaim agency over their conditions. Through tattooing personal reminders onto one’s body, affected individuals can anchor a sense of resolve about their conditions and their approaches towards treatment. The permanency of tattoos can also help relieve the cognitive dissonance between the continuity of a lifelong skin condition and the itinerant, unpredictable appearance of symptoms. Tattoos may simultaneously augment one’s group membership identity and situate affected individuals within wider communities of support. These personal and relational aspects of tattooing may further contribute to a deeper, more semiotically-engaged feeling of medical agency.

As a means of developing a sense of control, tattooing may assist individuals to inscribe personal meanings and health-related reminders onto their bodies. Some of the women who spoke with me noted how they felt rushed to find a cure for their condition, oftentimes subjecting themselves to physical harm, mental turmoil, and/or financial detriment. Kayla, however, used tattooing to remind herself to pursue treatment at a more agreeable pace. She explained her decision to get a tattoo for her vitiligo on her foot:

> “I got it to represent like, even though I wasn't born from birth with it, it's something that I just have to deal with. And like, taking it one step at a time, kind of thing. That was the meaning.”

Rather than attempting to resolve her condition as fast as possible, Kayla utilized tattooing to help her accept and acknowledge that her healing process would take time. Helping to guide her process of managing her condition, Kayla described her tattoo as a “reminder” that gave her instructions on dealing with the permanence of her condition. Other design elements of Kayla’s tattoos also related to instances when she viewed the aesthetics of her vitiligo favorably. Tattooing empowered Kayla with a somatic reminder about how to treat and view her condition when confronted with compromised medical agency.

The tattooed inscription of personal reminders may particularly assist affected individuals to resolve feelings of cognitive dissonance brought on by the transient appearance and remission of their skin conditions. Although the condition’s symptoms can disappear, the individual must treat their skin and body as if they continue to have the condition. Stephanie repeatedly detailed how her alopecia would affect her in “episodes,” as opposed to a sustained period of time. She explained how her tattoo operated as a reminder that her alopecia was a permanent condition:

> “My tattoo, I got to remember my alopecia, because sometimes I have it and sometimes I don't. So, the moments that I don't, the couple of years that I don't have it, and I have all my hair, it's a remembrance to remember alopecia and the struggles that it brought me.”

Through the permanence of her tattoo, Stephanie attempted to resolve the cognitive dissonance caused by having a permanent condition that presents symptoms in intermittent intervals. She noted that her tattoo helped to remind her of the permanence of her condition during a period when her symptoms had normalized: “It was a remembrance of, hey, you know, you could still always get it again. You know, it's still in your blood, you could still get it and all those feelings of, of having it again'' Despite her skin condition's transient appearance, Stephanie's tattoo certified that she was "never truly going to get rid of" her alopecia, allowing her to feel cognitive assonance. Stephanie's tattoo functioned as a physically inscribed reminder to take care of herself even when her lack of apparent symptoms suggested otherwise.

Alienation and isolation also figured as central themes among contributor narratives. The women who spoke with me repeatedly talked about feeling estranged from their former social identities due to stigmatization, embarrassment, and anxiety. For some contributors, support groups related to their conditions helped them to socialize with others and deal with health-related obstacles. While the meaning of her tattoo anchored the permanency of her skin condition, Stephanie designed her tattoo as a tribute to the support group she created for individuals with alopecia. The tattoo incorporated images related to Stephanie's support group, including a "blue ribbon" to signify alopecia and "wings" to represent support, arranged in the shape of a heart as an allusion to the name of her group. Stephanie stated that her tattoo symbolized "support for alopecia" and her involvement in a network of support. To this effect, Stephanie discussed how her tattoo honored the various relationships she had previous formed through alopecia and the future connections she hoped to build in the future. Stephanie's tattoo helped her to view herself as a member of the wider alopecia community. For Stephanie, tattooing emblemized the importance of her support group in managing her alopecia and helped her to identify with a group of others who shared her condition.

Tattoos, as sites of personal meaning-making, can generate self-selected reminders about how to view and treat one's skin condition. For one contributor, tattooing helped reshape their approach to healing and self-care. Another contributor utilized tattooing to resolve the tension between the permanency and transiency of their alopecia. Furthermore, tattooing can reify a sense of belonging and connection within a community of support. Through the inscriptive dimensions of tattooing, affected individuals can imbue their healing journeys with personal meaning and guide themselves on their route towards acceptance.

As individuals with skin conditions undergo the process of managing their conditions, they may experience a lack of agency in determining health-related outcomes. At a primary level, the appearance of a skin condition occurs beyond one's control. Meanwhile, the sparsity of effective medical options and their diverse array of risks can further exacerbate this felt lack of agency. Operating outside biomedical discourses, contributors to this study developed a range of strategies that promoted their holistic health and heightened a sense of self-determination. In this regard, body modification functioned as a tool for affected individuals to cope with the disempowerment from their conditions and to transcend their disenfranchisement from medical interventions. As modifying the body supported individuals in managing their health and wellbeing, contributor interviews suggest that body modification practices may also give rise to a renewed connection with oneself.

Bodily Sovereignty & Incorporation

"The wound is the place where the Light enters you."

– Rumi (Rumi & Barks, 2004, pg. 114)

Although body modification is generally presented as a process of marking meaning *onto* the body, it may also operate as a process of inscribing symbolic significance *into* the body. As Butler (1999) notes, dominant discourses often conceive of the body as a pre-discursive *tabula rasa* upon which cultural meanings are imprinted. Applying this frame to the presentation of skin conditions *on* the body, as opposed to *in* the body, contributors bifurcated the connection between their bodies and their conditions into distinctly separate entities. Intensifying a sense of both internal and temporal depersonalization, the trauma-related origins of many skin conditions can further aggravate this tension. Body modification practices, however, helped to widen contributors' corporeal boundaries and promote the process of incorporation as they worked to marry their skin conditions with their identities.

Losing the Embodied Self

All of the contributors in this study presented their skin condition as an identity threat. While the arrival of skin conditions can disempower affected individuals from expressing control over their bodies, Nardi (2005) and Kent (2000) also identified various social-identity threats that individuals with skin conditions may experience. The interrelatedness of these bodily and social identity threats complicated contributors' processes of incorporating their conditions. For the women with vitiligo, their skin conditions presented permanent changes to the skin, creating a longitudinal sense of bodily discontinuity. Contributors with eczema, psoriasis, and acne, on the other hand, described how the episodic appearance of their conditions evoked acute feelings of disgust and shock. Sketching a Kafkaesque description of her eczema's onset, Lauren stated, "I can remember telling my mom, I don't feel like, I don't look human, you know. I felt very, very negatively and very alone in that." Lauren's bodily transformation heightened a sense of otherness, influencing the relationship between her social and bodily identities. Kayla echoed Lauren's sentiment of feeling unrecognizable to herself: "You go and look in the mirror. And it's like a completely different . . . I felt like a completely different person . . . I just felt like I was losing part of myself." Kayla experienced additional challenges entering college, stating that she was "becoming a new person anyways." She claimed that, as a result of her condition and her development as a young adult, she felt like she was "losing" herself and "finding" herself at the same time. Contributors collectively shared similar experiences of troubled self-discovery amidst identity-threat. The appearance of a skin condition can destabilize one's physically embodied and socially embedded sense of self.

Depersonalized Bodies

In concert with reporting threatened self-concepts, each of the contributors in this study portrayed their skin condition as an oppositional force that countered their volition and hindered their bodily sovereignty. This separation between one's body and the skin condition located within it exemplifies Hunter et al.'s (2017) definition of the term "depersonalization" as an experience of feeling detached from one's sense of self (p. 1). For some contributors, their skin condition resembled a separate entity, de-coupled from their own embodied consciousness. Other contributors upheld medical explanations that interpreted autoimmune disorders as a series of self-inflicted bodily attacks. All of the contributors, however, unanimously described their condition as a consumptive energy that overpowered their free will.

Divorcing their skin conditions from their embodied sense of self, contributors represented the presence of their skin condition as an unruly and unwelcome bodily intruder. As a result, many of the women reported feeling subject to their condition's will. "I lost the self-control over my appearance. I have no control over my hair. It does whatever it wants," Stephanie explained, illustrating the effects of her alopecia's invasive and disempowering aspects. The lack of agency evident in Stephanie's reflection displays a depersonalized separation between her identification (or lack thereof) with her condition, on one hand, and the physical processes of her own body, on the other. Stephanie detailed her feelings of powerlessness: "It doesn't matter what you do or don't do to your hair. It just does what it wants." By stating that her alopecia "just kind of comes and goes whenever it wants to," Stephanie depicted her condition less as an integrated aspect of her own conscious embodiment than as a disembodied trespasser infringing upon her physical and psychological terrain. In personifying the condition as a foreign entity, contributors depersonalized their identities from their conditions, inhibiting their process of integrating their conditions as integral aspects of themselves.

Current medical discourses, meanwhile, frame skin conditions and “autoimmune illnesses” as perplexing processes caused by involuntary bodily self-harm. Contributors often described their experiences through this language of self-inflicted attack. “I didn’t understand why I feel like my body was like betraying me,” Lauren recounted. She continued to describe how her own “sweat” and “tears” irritated her eczema, stating, “It’s almost like you’re allergic to your own bodily fluids.” Discourses surrounding autoimmunity problematize the immune system, portraying immune function as both a vital bodily process and the harbinger of turmoil and suffering. Stephanie examined this cognitive dissonance: “I’m actually perfectly healthy. I’m actually so healthy, my hair follicles attack themselves.” The language of self-harm prevalent in autoimmune discourses positions the body’s immune function in opposition with its own wellbeing. Despite contributors’ attempts to promote their health, they often concluded that “you can’t because your body just doesn’t let you” (Sophie). In presenting the skin condition as a siege upon the body, contributors felt corporeally divided from their conditions and incapable of stopping their spread.

Extending this notion of self-injurious bodily overwhelm, contributor responses displayed a variety of narrative sequences that configured their skin condition as an overpowering force beyond their control. McAdams et al. (2001) describes “contamination sequences” as “the move from a good, affectively positive life scene to a bad, affectively negative life scene” (p. 474).

Contributors portrayed their skin conditions as an external force that "spoiled, ruined, contaminated, or undermined" their bodies' more idyllic previous state of health (McAdams, 2001, p. 474). In doing so, they characterized their conditions with *in vivo* terms such as, "riddled," "overtaken," and "flare-up," among others. Interviews also commonly featured lists of body parts that had been affected by the condition, as evidenced by Jacqui's description of her experience with a psoriasis flare-up:

> "It riddled my body. I had it on my eyelids, my labia, my, I mean, in the folds of my body in different areas . . . I was riddled with it and I had never been consumed by a skin condition so much as I was then . . . This weird thing with my body takes over my body, takes over my body . . . It's out of my control."

In describing feeling "consumed" by her condition, Jacqui conceived of her body and her condition as diametrically opposed forces. Accordingly, Jacqui felt that her body had forfeited its own self-determination to an outside authority. This externalization of the skin condition from the body challenges the process of constructing an identity that integrally includes one's health status and perpetuates feelings of bodily discord.

Influencing the social enjambment of selfhood, one's racial identity may further complicate the process of incorporation. While only one contributor in this study self-identified as black, she prominently discussed the troubled relationship between her vitiligo and her racial identity. Consistent with Porter and Beuf's (1991) findings, the abrupt hypopigmentation Natasha experienced with vitiligo threatened her self-image as a black woman. She recounted, "When the dermatologist told me, 'You have such beautiful brown skin,' I was like, 'Oh my God, I'm not going to be… I'm not going to be black. I'm going to be looking like a freak." At the moment of receiving her diagnosis, Natasha felt that the appearance of her vitiligo threatened the stability of her racial identity. She further noted how being a black woman highlighted the distinction between her body and her skin condition: “There’s a big difference between having vitiligo and not many people can tell you got vitiligo, versus you’re black and it's obvious that you got vitiligo.” In consideration of the visible contrast between her dark skin and lack of pigmentation, Natasha claimed that “owning” her condition was her only option: “You have to face it.” Affirming her identity as a black woman, Natasha concluded, “My color does not define myself. It’s my experience. I’m still a black woman, I know who I am. . . . I’ve always been black and I’m going to die black, period.” As a means of overcoming her vitiligo’s threats to her racial self-identification, Natasha repeatedly disqualified the socially-reinforced misconception that skin color determines racial identity. The visible changes in Natasha’s skin forced her to redefine the grounds by which she self-identified as a black woman, deprioritizing bodily presentation in favor of lived experience.

Contributors indicated that the appearance of their skin conditions ruptured their embodied sense of self. Depicting the condition as a foreign entity, contributors noted feeling conflicted about how to unify this external force with their identities. Advancing this language of oppositionality, they described their conditions as a series of self-inflicted attacks. While the notion of the skin condition as a separate entity enables individuals to clearly define one’s position in relation to their health-related issues, the biomedical framework of autoimmunity as self-harm problematizes the unconscious immunological processes of affected individuals’ bodies. Contributors additionally discussed feeling overtaken by their condition, alternatingly discussing their health problems as the contamination of a once-perfect state of health and the consumption of one’s body by an overpowering presence. Meanwhile, the appearance of a skin condition can challenge the construction of racial identity by creating tension between one’s bodily presentation and the cultural significations attached to one's body. The women in this study expressed how depersonalizing themselves from their skin conditions made them feel at odds with themselves. That said, the traumatic origins of many skin conditions can recall past events from which affected individuals may seek to detach.

Inscribed Trauma

> "Behind those spots is a story. . . . So many of us have been traumatized. We dealt with trauma. I've had, I've heard from so many people, they had a divorce; they developed spots. They've been raped or molested as kids; they developed spots. . . . They saw their own brother get shot in front of their front yard; they started developing spots. . . . Those spots that people view as beauty, there is a story behind them and it's not a pretty-ass story . . . It's not a pretty story. I have yet to have met a person with vitiligo and they're like, 'Oh, my life was normal. And I just poof, got these spots.' . . . No. . . . It's a story. Everybody has a story." (Natasha)

Exemplifying the phenomenon that Natasha identified above, all of the contributors to this study discussed how trauma and periods of emotional intensity aggravated their skin conditions. They disclosed how the appearance of their conditions spiked after experiencing sexual trauma, rape, emotional abuse, medical mismanagement, and/or grief. For some contributors, the presentation and improvement of their conditions directly corresponded with their emotional processing of trauma and loss.

Auster (2012) notes that scars are "letters from the secret alphabet that tell the story of who you are" (p. 5). Slatman (2016) extends this observation: "Indeed, scars are marks of something that has happened to your body and as such they refer to something in the *past*. But they also incarnate the body's *present* meaning in the sense that they can represent bodily difference" (p. 348). The physical change to the body that contributors experienced simultaneously evoked past traumas and present stressors. As Auster (2012) might say, the skin condition can operate as a reference to previous and current emotional trials.

In accordance with Auster's (2012) reflections on scars, the women who shared their stories with me interpreted the current presentation of their skin conditions as projections of traumatic experiences from the past. Describing the influence of grief on the severity of her psoriasis, Jaqui noted a direct correspondence between her condition and her processing of emotional trauma. She recalled how her psoriasis improved after spreading her father's ashes:

> "Once my dad passed and the biggest stress of everything was over, I think it was about a year later that I spread his ashes. So, I think it took a year for me to get out of my head and be okay with him passing. And I just drove to California, spread his ashes in the ocean, and it seemed like, because I remember, I remember the saltwater burning my skin. This is the open wounds, you know, it burns. And so, I was still kind of in pain and suffering from the psoriasis at that time, but it was shortly thereafter that I think that it started finishing."

Entering the ocean with a flare-up, Jacqui felt and released the sting of both her psoriasis and her father's passing. Jacqui's story details the extent to which emotions influence the development and progression of skin conditions. In this sense, the appearance of a skin condition may develop as the inscription of trauma both *on* and *within* the body. Viewing the skin condition after its traumatic context of origin, then, invokes the persistence of such trauma into the future, posing potential psychological and emotional challenges for individuals as they incorporate their conditions as part of their identity.

In tandem with marking past trauma, skin conditions also exhibit the individual's present internal state. The contributors to this study indicated that their skin conditions externally displayed the affective qualities of their interior experiences. Lucia described her acne as a "mood ring" for her holistic state of health:

> "It's almost like a mood ring. If I'm interested in knowing if . . . I know I need to drink more water, and I'm like, 'My gosh, the body needs more water.' But it's a very big indicator of having stressful situations, or touching my face, or like needing more water, and all these different things that I shouldn't be doing."

Despite affording Lucia the ability to gauge and direct the management of her skin condition, this outward exposition of internal distress often felt intrusive for her. She went on to describe an experience of interviewing for a new job during an acne flare-up, noting that "your face" is "a window to your whole person." Although the severity of a flare-up can offer individuals insight into their care regimens, the condition's inconvenient "dysappearance," to use Leder's (1991) term, involuntarily exhibits the affective qualities of one's internal experiences. This external expression of one's physical, mental, and emotional state prevents affected individuals from viewing their skin conditions as merely physical occurrences. Instead, the women who took part in this project repeatedly described the appearance of their skin conditions as "reminders" of current problems and past traumas. This referential dimension of skin conditions can position the skin condition at the center of one's attention, obstructing the process of bodily incorporation.

Incorporating the Condition

The term "incorporation" refers to the process of integrating one's lived experiences and bodily inscriptions as part of oneself (Auster, 2012). Applied to the presence of a skin condition, "incorporation" involves moving the condition from the focal point of attention into the “corporeal background” of one’s consciousness, as Leder (1990) might say (p. 1). In order to incorporate their skin conditions as integral aspects of themselves, contributors to this study employed a range of strategies and frameworks complemented and cultivated by their body modifications.

It should also be noted, however, that body modifications may complicate the process of incorporation. Several contributors shared their regret over their tattoos and expressed desire to cover or remove them. That said, the option to modify the body allowed the individual the ability to self-select their physical changes and exert bodily agency.

Interrogating the expression of sovereignty, Jacques Derrida used the biomedical term *autoimmunity* to explore the nature of self-control. He writes:

> “Here is where the cruel autoimmunity with which sovereignty is affected begins, the autoimmunity with which sovereignty at once sovereignly affects and cruelly infects itself . . . It is not some particular thing that is affected in autoimmunity, but the self, the ipse, the autos that finds itself infected. As soon as it needs heteronomy, the event, time, and the other” (Derrida, 2005, p. 109).

In this sense, the self-effacement of the autoimmune body extends beyond mere biology and affects the ground of identity itself. As Andrews (2020) notes, the experience of autoimmune illness generates “a paradoxical opening (from) closure of the sovereign self” (p. 103). The women in this study discussed their passage through this paradoxical opening via body modification. In doing so, many contributors echoed Andrews’ (2020) reflections on the experience of hyper-immunity:

> “As my body attacks itself, protection of the notion of myself as an able, autonomous, whole, healthy and secure self is demanded; and yet the more I defend this notion of myself, the more I destroy it – the harder I work, the less I *work*” (p. 104).

According to Derrida, in order to maintain the self, or the *autos*, one must deconstruct one’s own unified identity by admitting difference. For the contributors in this study, auto-immunizing difference meant “owning” their skin condition as both a corporeally integrated being and autonomous, sovereign entity.

Each of the women in this study, however, noted that their voyage to self-acceptance was a compulsory one. Natasha explained:

> “The deal is you can’t control your vitiligo. I can’t tell my vitiligo. Hmmm, I want this spot right here; I want a little bit more spots right here on my breast, so I can be a lot more intriguing for photo shoots. You can't control it. You can't control it, but you can either accept it or not . . . And when you don't accept that, that, that the, the vitiligo has complete control over you, which makes you complete at loss of yourself. You lose your sense of self because you're letting the vitiligo define you instead of you defining the vitiligo itself.”

Although many of the women who talked with me claimed that they had accepted their condition, they described the predicament of acceptance as a mandatory situation without choices. A lack of control permeated various dimensions of contributors’ lives. Additionally, medical providers, like Kayla’s dermatologist, may present acceptance as a veritable medical option. “[My dermatologist] told me, I pretty much had three options with it,” Kayla explained, “She was like, you can restart your treatments, you can bleach your skin, or you can just own it.” In order to “own it,” however, participants confront the reality that they have no other legitimate alternative than accepting their new, fundamentally changed selves. In effect, many of the women in this study claimed that the constraints of their conditions accelerated their journeys to self-acceptance. Natasha stated that her vitiligo had been “an actual weird saving grace because vitiligo helped [her] to love [herself].” She recounted, “I didn’t want vitiligo, but then again, vitiligo forced me to love myself and now I have high self-esteem.” Through the closure of her previously embodied identity, Natasha’s vitiligo created a “paradoxical opening” through which she cultivated self-love. The constraints of skin conditions challenged affected individuals to radically accept themselves and incorporate physical qualities that had previously been considered “flaws.” Many contributors shared Sophie’s rumination, “It's out of my control. So, why would I hate on something that I cannot control anyways?” Despite, or perhaps because of, the lack of alternative options, body modifications may facilitate affected individuals to arrive at self-acceptance.

In reflecting upon this process, several of the women in this study noted that their body modifications helped them to accept themselves and their bodies. In an explicit way, Jacqui affirmed her self-love by tattooing the image of a heart with a banner that read her own name on her back. While Jaqui’s body modification directly reminded her to “always love” herself, other contributors cited more tacit benefits of their body modifications’ role in self-acceptance. Reflecting on the influence of her tattoos on her identity, Lauren said that she viewed body modification as a “tool” that helped her reach “a place of self-acceptance.” She continued to describe how her body modifications assisted her in dealing with eczema flare-ups:

> “There are still times when I have a bad flare and I’m embarrassed, but I think I can work through it better now and I’m less dramatic about it. And it helps; I’m better about remembering what I do like about my body.”

By giving her a positive counterpoint to her eczema, Lauren's body modifications helped her work through the emotional turmoil of flare-up episodes. Offering advice to others in similar circumstances, she suggested,

> "Reframe things to focus on parts [of your body] that you do like, and if perhaps you're struggling with that process . . . modify the things that then you're controlling and work on accepting the things out of your control."

Lauren's body modification helped engage a dialogic reading of her body. During times when she focused on her eczema, her body modifications provided a parallel vantage point. Although some might view Lauren's body modifications as mere *accessories* added to her physical body, her tattoos became *accessory to* her process of self-acceptance. Consequently, she composed a more integrated identity that infused her skin condition as an indispensable, albeit uncontrollable, aspect of her identity.

While individuals may resolve their relationship to their bodily presentation in physical space, they may simultaneously struggle to narrativize their bodily metamorphosis across time. The arrival, progression, and remission of skin conditions may disrupt affected individuals' capacity to locate themselves within a consistent life narrative. The arrival of many skin condition may designate a permanent change in one's health status, but the presentation of such conditions may also appear and disappear in unpredictable intervals throughout the life course. Subsequently, affected individuals may experience a disjuncture in their process of identity construction across different phases of their lifespan. In order to wrestle with these temporal incongruencies, affected individuals may employ body modification as a sense-making tool. The permanency of body modifications may simultaneously circumvent or complement the temporal ruptures affected individuals may feel in relation to their skin. This temporal interplay may assist individuals in establishing new self-concepts and life story narratives.

Often presenting as itinerant issues, skin conditions can challenge affected individuals as they grapple with bodily transience and disruption. Conditions like acne, psoriasis, and alopecia can appear and re-appear in flare-ups or episodes over time (Beckett, 2015; Obradors et al., 2016). Although vitiligo may share similar periods of intensity, the hypopigmentation from the condition often permanently remains (Arianayagam & Ryan, 2016). In both cases, however, affected individuals may experience a feeling of bodily discontinuity as they reckon with the transient presentation and disappearance of their skin conditions. As Lucia mentioned, “the hard part with having” a skin condition “is that you’re forever changing; it’s different every day.” Expanding on how this feeling of transience can persist over longer periods of time, Stephanie explained how the episodic nature of her alopecia caused her distress: “All of a sudden, it flares back up and you’re like, ‘Why me?!’” This unpredictability can sever the relationship between affected individuals and their bodies. The integrity of this connection, however, operates as a primary mode of identity construction.

Likewise, skin conditions may fracture the unity and stability of the self over longer periods of time. Reviewing the visible changes to her appearance, Natasha described looking at old photos of herself as a “surreal” experience: “I could tell what year it was based off of where the spots were located or how reduced the spots were.” She further explained how the development of her vitiligo directly corresponded with undergoing traumatic experiences: “I can tell, pre-rape and post-rape and, ‘Oh, this was 2017 because this is getting a lot, this was a lot thicker,’ and you know, it’s 2020, it’s a lot smaller.” The progression of vitiligo can induce a sense of discontinuity from one’s personal history. Meanwhile, the possibility of undergoing additional changes to one’s appearance threatens individuals as they confront future challenges and stressors, as Natasha humorously noted: “I joked with my friends that once I got laid off, I was like, guys, don't be surprised if I'm just completely white.” The indeterminacy of a skin condition’s future spread can present unforeseen challenges as individuals wrestle with each new recurrence and reappearance of their condition. Grappling with the itinerancy of one’s skin conditions featured as a significant theme across contributor responses, illuminating how the permanency of body modifications may help anchor individuals’ sense of corporeal continuity.

In order to solidify their sense of self amidst the transience of their skin conditions, contributors employed body modifications as permanent somatic anchors. To this effect, body modifications aided individuals in establishing a sense of continuity amidst unpredictable physical changes. Kayla’s foot tattoo aided the incorporation of her condition through the use of a “birthmark color” to represent her vitiligo as an inherent aspect of her body. She explained that her color selection sought to remind her that her vitiligo had become a part of her, as if she had been born with the condition. Countering her alopecia’s itinerant presentation, Stephanie’s tattoo helped remind her that her healing journey may unfold through a lifelong process: “It's like a remembrance of, ‘You still have it. Don't be ungrateful that you have your hair right now.’” She added, “My tattoo is just a rememberance that I have alopecia and that it's always going to be there.” From Stephanie’s perspective, body modification helped to resolve the disturbing notion that “once you get [alopecia], you can get it again, or you can never get it again.” The blue ribbon and design elements in Stephanie’s tattoo further helped her to incorporate her alopecia as an enduring part of her identity.

Tattoos as permanent body modifications differ from piercings in that piercings generally can be more easily removed. Despite having the option to take out her genital piercing, however, Jacqui elected to keep her body modification for life: “That same piece of jewelry that was put in in 1996 is still in there. I won’t change it out . . . It’s staying; I’m dying with it.” Through the permanence of their body modifications, contributors established bodily continuity, mitigated psychic disruption, and maintained their sense of self.

Enfolded in the correspondence between permanency and transiency, body modifications may also assist affected individuals through the process of “habituation.” Slatman (2016) explained that this term “implies a certain shift in the way one endows meaning to one’s own body” by becoming “used to” physical disruption (p. 348). Applying Slatman’s (2016) research among women incorporating mastectomy scars, this study traces a similar trajectory among individuals with skin conditions using body modification as an instrument of habituation. Contributors repeatedly described how their body modifications had promoted their ability to reckon with bodily changes by habituating them to both the permanency of their conditions and their own physical mutability. Nearly all of the women in this study employed the phrase “getting used to it” when discussing their skin conditions. Body modifications featured as central elements in this process by inoculating changes in one’s “embodied self-experience” (Slatman, 2016, p. 348). On a social level, Stephanie explained that her skin conditions and tattoos often warranted “the same type of stares.” In this regard, Stephanie’s body modification allowed her to acquaint herself to the public eye. By providing a controlled container to proxy personal metamorphosis, body modifications may assist individuals to incorporate changes initiated by their skin conditions.

As affected individuals work to integrate their past, present, and future within the construction of their identities, body modification may encourage the process of sense-making and moderate the effects of bodily disfluencies in one’s personal life story narrative. The negotiation between the permanence of body modifications and the transient presentation of skin conditions may further give rise to various perspectives on the body that facilitate the process of incorporation.

Body modification practices may support affected individuals in re-conceptualizing their bodies in ways that mitigate feelings of powerlessness and encourage somatic integration. All of the participants in this study portrayed their body modifications as methods for seizing corporeal control in response to the arrival of their skin conditions. By providing an avenue for the articulation of one’s agency, body modification practices operated as mediums for self-expression that simultaneously gave form to multitudinous personal meanings and undermined the fixity of bodily boundaries. Citing the significance of their body modifications in developing new outlooks on the body, some contributors presented their skin conditions less as burdensome albatrosses to be “cured” and more as innately beautiful works of art to be celebrated and aesthetically appreciated. For one woman, body modification additionally restored what she felt to be her true bodily identity. Body modifications promoted the development of adaptive coping perspectives that helped contributors to incorporate their skin conditions as integral aspects of their identities.

In response to the lack of agency associated with many skin conditions, contributors employed body modification as a means of exercising control of their embodied identity. Expressing personal will through body modification may suffuse the body with identity-affirmative inscriptions. Natasha described this correlation between bodily self-determination and identity construction:

> "I see my tattoos as a form of control over my body because I added that. I wanted that and I got what I wanted and it makes me feel beautiful . . . And it's part of me because it's what I wanted. Did I want vitiligo? Hell, no. I didn't ever want vitiligo."

From Natasha's vantage point, the agency garnered through her tattoos counteracted the loss of control brought on by her vitiligo. Individuals with skin conditions may be more inclined to incorporate and accept their conditions through body modification's expression of choice, as Lauren noted: "That's probably where the satisfaction comes from that, like, this is a piece of my body that I've chosen." Although contributors had portrayed their skin conditions as outside entities, the ability to influence the body via body modification afforded them the ability to re-integrate their identities and assert their corporeal agency as embodied selves.

In conjunction with gaining control, contributors envisioned their body modifications as a means through which they expressed themselves. Follett (2009) draws upon Bakhtin's (1984) concept of the "grotesque body" to describe how tattooing projects internal meanings that paradoxically incarnate contradictions, interrogating boundaries between the interior and exterior self. In the Bakhtinian sense, tattooing parallels the "grotesque" character of skin conditions in that they both outwardly inscribe the body with internal meanings and feelings. Contributors noted that this grotesque faculty of tattooing may serve identity-affirmative purposes. "I get these tattoos, again, as a reminder of telling my story of who I am," Natasha remarked, asserting the utility of body modification in narrativizing her identity. Most of the study's contributors also discussed how their tattoos reinforced their self-image by portraying their favorite literary characters, animals, and pastimes, among other themes. Portraying body modification as a tool for identity construction, Kayla presented her tattoos as mediums of self-expression:

> "I think it is a really important part of accepting your body and who you are, and you're able to show your artistic expression through tattoos . . . Each person has their own artistic value and how they perceive themselves and show themselves to others. And I think getting tattoos is a really good way to do that."

In Kayla's experience, tattoos enabled her to display how she viewed herself and wished to be seen. Kayla's self-expression through her tattoos differed from other contributors since her tattoo dedicated to her vitiligo engaged meaning through its selective placement on her foot. She claimed that the tattoo served as a reminder for her to "take it one step at a time." In effect, Kayla's body functioned as a semiotic ingredient in the creation of her tattoo's meaning. Tattooing, in this way, permits affected individuals to somatically express and enunciate their identities. For many contributors, giving voice to the body through body modifications helped to silence the whispers of stigma and the drone of medical phrases like "autoimmune," "incurable," and "irreversible."

Scaffolded by the process of habituation, some of the women who talked spoke with me conceptualized themselves as constantly changing works of art. Habituating herself to the loss of pigment spurred by her vitiligo, Natasha metaphorized her body as an aesthetic artwork: "I view my body as a canvas. I call myself a work of art. So, I think [the tattoo] enhances [the vitiligo]." She repeatedly referred to herself as a dynamic "canvas." From this perspective, each new spot on Natasha's body complemented her personally unique aesthetic. In this way, Natasha's body modifications helped her to aestheticize the appearance of her vitiligo. She remarked how her tattoos and work as a model helped her view herself as an ongoing work of art: "Every time I get back with another old photographer, they're like, 'Whoa, I didn't notice this spot from this year. You got a new spot,'" to which she responded, "'Duh . . . I'm evolving dude, I am so evolving.

Like, you better take some more pictures of me while you can.'" Natasha's tattoos assisted her in neutralizing the development of her skin condition as a process of personal evolution. By aestheticizing her body, Natasha strengthened her ability to incorporate emergent transformations in her skin:

> "My looks change every day, who I see in front of that mirror tonight is going to be completely different tomorrow . . . And that's just life, you know, it's like everybody gets a wrinkle a day. Why cry about it? It's life. I'm evolving."

Through viewing herself as a canvas, Natasha accepted changes in her skin as a continually transforming "work in progress."

In a more indirect way, Sophie incorporated her vitiligo by aestheticizing its relationship with her tattoos:

> "If I get a tattoo on my white spots, for example, the colors look really nice because it's way brighter . . . So, it looks pretty dope. So, if I get something on white spots, I usually try to get like something red."

Rather than viewing her vitiligo as a disfigurement or deformity, Sophie used body modification to frame her vitiligo as an aesthetically elevating feature. Extending the notion of the "body as project," several contributors viewed their skin conditions as artistic complements to their body modifications, endowing them with the ability to beautify, control, and make sense of their changing appearance.

While other contributors envisioned their bodies as works of art, Lucia represented her plastic surgery as a process of returning to her true face. As if suffering from a birth defect, Lucia stated, "My nose was kind of like . . . something that I felt like I was born with . . . It felt like a sixth toe. Like, it just didn't ever feel like it was supposed to be there." By undergoing plastic surgery, however, Lucia retroactively resolved this problem. She described the “big reveal moment” of seeing her face after the procedure: “And I was like, this is, this is my new face . . . It felt like it was the face I was supposed to have.” In going through plastic surgery, Lucia felt as if she had restored the natural order of her body and corrected the accident of her nose.

Extending this feeling of returning to her foreordained body, Lucia referred to her new face as her “adult face.” Alongside this term, Lucia discussed a reversed timeline of beauty and human development in which she grew into being more beautiful as she aged out of youth. Lucia noted how she liked her “developed-aged face” more than “when people were supposed to be young and youthful and beautiful.” She commented, “It's kind of weird equating youth and beauty, whereas I kind of saw it as the opposite, cause my youthful face at 21 was not the face that I necessarily liked.” Instead, she considered her “adult face” as her “confident face.” She added, “The opposite of youth equals beauty.” In this sense, body modification allowed Lucia to feel bodily integration, reversing her previous conceptions about the relationship of beauty with youth. As a result of undergoing plastic surgery, Lucia incorporated her beauty as an inseparable dimension of her identity. Although her acne continued to present challenges, Lucia mentioned that her plastic surgery boosted her confidence: “Even if my skin is horrible, I feel a thousand times more confident to go out with my naked face.” Influenced by the effects of her plastic surgery, Lucia’s self-identification as beautiful allowed her to incorporate her identity as a confident aging adult.

While individuals with skin conditions experience barriers to the process of constructing embodied identities, body modifications may amplify a sense of wholeness. Contributors to this study reported feeling as if they had lost part of themselves to their condition. Similarly, they discussed their skin conditions as depersonalized entities detached from their own bodies.

Complicating this dynamic, the traumatic origins of skin conditions pinioned contributors against the psychologically exhausting past and the emotionally exposed present. In remedying these barriers to embodied identity construction, contributors employed body modifications as supplements to an array of strategies and perspectives that promoted a sense of integration and bodily incorporation of their conditions. Although body modifications may fortify one's personal relationship to their body, individuals with skin conditions may confront broader social challenges.

Wielding the Spectacle

Contributors to this study unanimously reported that their skin conditions attracted unwanted attention. Since skin conditions perceptibly affect one's external appearance, they may garner public attention and give rise to stigmatization. Using Goffman's (1963) terms, skin conditions may be classified as either "discredited stigma" that cannot be concealed or "discreditable stigma" which may be covered or hidden from visibility. The stigmatization of skin conditions engages Goffman's (1963) exploration of "stigma management" strategies that may assist individuals in attempting to pass for normal. Although the women in this study did employ various "stigma management" strategies in their "presentation of self," many of them conveyed the implementation of such strategies as more than mere reactions to public ridicule (Goffman, 1963). In contrast, contributors displayed a range of socially adaptive behaviors and perspectives that operated as assets in broad professional and relational domains.

Sophie reflected on how "some people literally stare" at her vitiligo or "start talking and turn around" or "literally walk behind [her] so they could keep watching [her]." She continued, "I definitely feel sometimes like I'm in a zoo, like a zoo attraction." This sense of being dehumanized and constantly watched, as a zoo animal, underscores the heightened sense of otherness affected individuals can often feel in relation to their conditions. Kayla similarly addressed her strained relationship with the public gaze: “I never noticed how easy it is to spot when other people are looking at you . . . I’ll notice when people look over at me . . . They think you don’t notice, but you do.” This feeling of being continually watched elicits Jeremy Bentham’s (1791) conception of the “panopticon,” a revolutionary prison design in which the inmate undergoes the constant threat of surveillance. Contributor responses suggest that affected individuals may implement a variety of strategies to dim or brighten the spotlight on their conditions, in contingency with contextually advantageous criteria.

Misdiagnosis as Identity Threat

While many contributors experienced stigmatization for their skin conditions, they also fell subject to stigmatization through a range of misconceptions and predispositions others held about their conditions. As interview responses indicate, the majority of psychic distress contributors experienced derived from misguided assumptions that other people made about their conditions. Most significantly, misdiagnosing the condition appeared as a prevalent problem, as other people misconstrued contributors’ skin conditions with an array of medical and intersectional misinterpretations. Several of the women repeatedly lamented the frequency and severity of these misdiagnoses, noting how these mistaken evaluations posed significant threats to their identities.

As a result of the lack of public knowledge about skin conditions, many contributors claimed that people often misdiagnosed their condition as a different form of illness. Each of these misdiagnoses conjured a range of stigmatizing impressions and social connotations. Most notably, contributors presented identity protection and restoration as the primary effect of stigmatization. In response to misdiagnosis, affected individuals may feel alienation and receive misguided evaluations of their conditions.

Several contributors discussed the prevalence of contagion-related concerns. Responses ranged from Lauren being judged at a pool party to the following experience from Stephanie,

> “We decided to go to Walmart before we went to the Lake and I forgot that I didn't have my wig on . . . And I ended up running into a little kid there inside Walmart and the mom grabs the hand of the little kid and goes, ‘Don't touch her! She might be contagious.’”

Being misdiagnosed as contagious mislabels the affected individual as a public problem. Some of the women described personal, face-to-face interactions where contagion-related misdiagnoses interfered with their social engagements. Other contributors, however, recounted times when contagion-related misdiagnoses had been more difficult to clarify and redirect. Extending beyond person-to-person incidents of misdiagnosis, Kayla talked about a time when a friend of a friend in college spread misinformation about her vitiligo being contagious: “He was on the football team at my school and he decided to tell everybody . . . And he decided to tell them all, like, my vitiligo was contagious and I found out about it.” In the aftermath of this experience, Kayla then attempted to dispel the rumor across campus, explaining that her condition was a noncommunicable issue. She noted that she felt uncertain whether her efforts had worked to adequately clear her reputation among the student body.

While contagion-related misdiagnoses presented significant hurdles, other contributors shared experiences when their conditions had been misinterpreted as potentially terminal issues. “People a lot of times think I’m a cancer patient,” Stephanie reflected, “Because I have no hair. so, do you think I'm going through chemo? They're like, ‘Oh, are you going through a remission?’” Stephanie discussed how her baldness from alopecia caused people to assume she had cancer. In contrast to the severity of a cancer diagnosis, alopecia is often labeled and treated as a "cosmetic" issue. As a result, affected individuals may feel disqualified from sharing about their struggles with their changing appearance. This process of misdiagnosis and medical disqualification discouraged Stephanie from talking with others about the challenges associated with losing her hair. She commented,

> "I think a lot of people like, say like, 'Get over it. It's just hair.' Or, 'It's just skin or whatever it is.' And it's like, it's so much more than that because, you know, society thinks it should be that way . . ."

After learning that she had alopecia, people often then encouraged Stephanie to "be grateful" that she didn't have a terminal illness.

> "A lot of people say, at least you don't have cancer. 'It could be worse, you know, it's just hair.' And it's like, if it's just hair, then why do people give me so many fricking stares? . . . Why can't they just pass me by like a normal person?"

Confronting stigma, Stephanie felt simultaneously exposed and unseen as her alopecia garnered unwanted attention that subsequently invalidated her experience.

While Stephanie was misdiagnosed due to medical misperceptions and biases, Natasha encountered additional stigmatization from people attributing her vitiligo to perceived moral failure and sin. She mentioned that other black people in her "own community" had mislabeled her skin condition as a religious punishment, claiming that her vitiligo was "a form of leprosy" that developed as "a curse from the Bible." Natasha explained, "They use the Biblical quotes and they are like, 'Oh, that's leprosy . . . You're not supposed to look like that. You know, that's a curse." This explanation of moral failure complicated Natasha's expression of identity, since members of her "own community" made her feel as if "not everybody's going to love you; not everybody’s going to embrace you.” The stigmatization Natasha experienced threatened the integrity of her social identity within her community.

Misdiagnoses may extend beyond mere medical misevaluations and disidentify intersectional dimensions of the self. Contributors reviewed experiences in which their skin conditions caused others to misperceive intersectional aspects of their identities, such as age, race, and socioeconomic status. Lucia commented,

> “I’ve had a few times people ask me if I’m waiting, like in a lobby or something, they’re like, ‘Oh, like, what are you doing?’ I’m like, ‘Oh, I’m here for a meeting.’ And they’re like, ‘Oh, are you an intern?’ I’m like, ‘Oh, no, I’m meeting with this person.’ And they’re like, ‘Oh, great. You starting to look for colleges next year? . . . Like the conversation led. So, I was like, do you think I’m 17?”

She continued to explain that she worried that her acne may spoil her professional status because it makes her “look like a teenager.” Lucia elaborated, “I don’t want to come across that I’m 17 . . . Because I felt like I was so immature at 17. Like, I don’t want to be reverted back to that when I go [to work]. I’m not 17.” The professional risks associated with Lucia’s acne jeopardized her social identity.

While Lucia worked to clarify her age, Natasha experienced threats to her racial identity. She reflected on the ignorance she confronted that challenged her to prove her blackness,

> “I don't like how people have this box of what defines you as black or you're not black enough . . . Sometimes that can lead to some form of ignorance from your own community. ‘Cause if they're not used to it, they're thinking in their heads, ‘Oh, you bleached your skin and that's what happened.’ And it's like, no boo, I did not bleach my skin. This is actually a skin condition.”

Natasha continued to list a series of questions she had received from others conflating her condition with racial meaning: “What is your ethnicity? Are you black? Are you white? Or are you bi-racial? Because you just didn't mix all the way?” In anticipation of and response to these racial misdiagnoses, Natasha utilized both “tension management” and “impression management” strategies as a means of protecting and maintaining her social identity as a black woman (Goffman, 1963).

The medical and intersectional misdiagnoses contributors received point to Goffman’s (1963) discussion of various “tension management” and “impression management” strategies, as well as the “techniques of information control” that stigmatized individuals might employ to preside over the spread of information related to their stigma (pp. 91-92). In some cases, affected individuals can either cover or directly converse with others about their stigma. Whereas, in instances such as Kayla’s experience addressing rumors at her university, stigmatized individuals may feel required to implement more strategic “techniques” for “managing crucial information” about themselves (Goffman, 1963, p. 92). In the following sections, I explore how contributors utilized body modification to facilitate the management of social interactions.

Tension Management

According to Goffman (1963), when a stigmatized individual interacts with someone who does not share their stigma, the stigmatized person is often expected to make the normal person feel comfortable. In the meantime, the normal person will ignore the stigmatizing trait. Goffman (1963) comments on this interaction between “stigmatized” and “normal” individuals:

> “We are likely to give no open recognition to what is discrediting of [the stigmatized person], and while this work of careful disattention is being done, the situation can

> become tense, uncertain, and ambiguous for all participants, especially the stigmatized one" (p. 41).

In order to reduce this interpersonal strain, stigmatized individuals may implement various tension management strategies. Many contributors echoed Lauren's concern that "people wouldn't know what [her skin condition] was" and "would be distracted by it," assuming that she looked "unhealthy." She reflected,

> "If you don't know what it is, I feel like it's so distracting . . . Like, if I'm trying to . . . talk or have a conversation about one thing, but is that person listening or are they being really distracted by what's happening on my face? I guess I feel insecure, paranoid about that . . . I feel like it's distracting and I feel embarrassed by that . . . Whatever I'm saying is coming second to my appearance in that moment."

The spread of Lauren's condition across her body prevented her from simply covering her condition. Although other contributors' stigma presented in varying levels of obtrusiveness, each of them discussed the significant communicative labor required of them in social situations. Consequently, the contributors in this study developed a range of strategies to inoculate and minimize interpersonal tension brought on by their conditions.

Outlining the process of preventatively addressing stigmatizing traits, Goffman (1963) developed the concept of "disclosure etiquette" (p. 117). When employing "disclosure etiquette," the stigmatized individual "introduces his failing as a topic of serious conversation, in this way hoping to reduce its significance as a topic of suppressed concern" (Goffman, 1963, p. 117). He illustrated the situation of an injured man who may choose "to relieve" the "social strain" of his condition and "gain greater acceptance" by premonitorily initiating "discussion of the condition" (pp. 117-118). Reflecting on the process of enacting "disclosure etiquette," the women who shared their experiences with me examined the importance of “breaking the ice” about their condition.

For contributors like Lauren, directly acknowledging one’s condition operated as a primary method to mitigate interpersonal tension. Lauren detailed her process of “running [her] own PR” in which she explains her condition to others, reassuring them that her eczema was “something [she] was born with” and that “it’s just really dry skin.” She noted,

> “It looks horrifically disgusting. But like, I'll kind of come in and just like acknowledge that I understand . . . Like, ‘Yeah, I see it too.’ I've always kind of, even from a young age, told other people what it was.”

As many of the women expressed, continually “running” one’s own “PR” can become exhausting and may be accompanied by severe social isolation. Contributors repeatedly discussed calling out of work or skipping holiday gatherings in order to bypass stigmatization and social pressures.

In this regard, body modifications may assist stigmatized individuals in reducing the communicative labor of managing interpersonal tension. Stigmatized individuals often must navigate fraught interpersonal interactions and determine the appropriate moment to publicly acknowledge their conditions. To this end, body modifications may provide a neutralized “talking point” for individuals to initiate conversations about their bodies. “When people comment on [my tattoo],” Kayla explained, “they're like, ‘Oh, like, let me see your tattoo!’ Or like, ‘Did you just get that?’ Or, ‘Is this something like that?’” Receiving a compliment or starting a conversation around her tattoos made Kayla feel better about her condition:

> “Because it's like, it also makes me think about my vitiligo, though. Cause it's like, ‘Okay, you know, you're noticing the tattoo. But, I know you're noticing the vitiligo . . . And, I get positive things on both I would say.”

In alignment with several other contributor responses, Kayla’s tattoos operated as an “ice breaker” for talking with other people about her body. These conversations often began with exchanging compliments on tattoos and later pivoted to address her skin condition more directly.

In a similar way, Natasha used her tattoos as a conversational tool for discussing her condition and racial identity. Conversations with others offered Natasha the opportunity to “break it down to them” and educate others about race and her condition. She reflected on an interaction with a child who was staring at her vitiligo and tattoos:

> “And I was like, ‘Oh yeah, I'm a superhero. My power is that I can change colors.’ And they're like, ‘Whoa.’ But they're intrigued by it. And then I break it down to them. I say, you know, behind your brown skin is this color. And you know what that means? We're all the same color at the end of the day. And their heads explode.”

Natasha’s tattoos attracted an increased level of attention to her body. In doing so, they equipped Natasha with the ability to disclose her condition and clarify misconceptions and misdiagnoses about her racial identity. While Natasha used her tattoos to alleviate tension, they also enabled her to more readily educate others and engage in intercultural discourse.

“One method of self-disclosure,” Goffman (1963) notes, “is for the individual voluntarily to wear a stigma symbol, a highly visible sign that advertises his failing wherever he goes” (p. 100). Goffman (1963) adds that “stigma symbols have the character of being continuously available for perception” (p. 101). As permanent markings of the skin, tattoos may function as “stigma symbols” by visually disclosing the individual’s condition. Through this evident disclosure, contributors used their tattoos to operate as sites for education and public dialogue about their conditions.

The blue alopecia ribbon tattoo on Stephanie’s shoulder emblemized her connection to her support group. By clearly representing her status as someone with alopecia, Stephanie’s blue ribbon functioned as a “stigma symbol” (Goffman, 1963, p. 100). When people were unfamiliar with the symbolic association between the blue ribbon and alopecia, Stephanie used this lack of knowledge as an opportunity to educate others and disclose her condition. When people asked her what her tattoo meant, Stephanie felt “more able to explain, ‘Oh, well, that's my alopecia tattoo . . . Alopecia is an autoimmune disease.’” She noted that her tattoo allowed her “to go into it a little bit further.” In this sense, Stephanie’s tattoo functioned as a “breaking ice point.” From Stephanie’s perspective, her tattoo provided an opportunity to educate others and potentially undermine the prevalence of stigma associated with her condition.

For many contributors like Stephanie, each public interaction related to their condition represented an opportunity to teach others and undo stigmatization. Describing a typical conversation initiated by her tattoos, Stephanie recalled a time that she was walking in Walmart with her head shaved and her tattoo showing:

> “And someone pointed at my tattoo and goes, ‘Oh my gosh, your tattoo is so pretty.’ And then I was able to discuss, ‘Oh, it’s Alopecia. That's why I'm bald. It’s an autoimmune disease where you lose your hair. So many people in the world have it. Not many people know about it. I have my own support group. You know, if you know anyone that suffers from hair loss, feel free to have them reach out to me.’”

As opposed to hiding or covering her condition, Stephanie’s tattoo intended to attract attention. As a result, she simultaneously disclosed her condition and managed the preliminary tension. In this way, Stephanie used her tattoo to “keep the stigma from looming large” (Goffman, 1963, p. 125). Through similarly educational communicative events, Stephanie advertised her support group and positioned herself in a supportive role for others who may suffer from the same condition.

In response to stigmatization and the scarcity of public awareness surrounding skin conditions, several other contributors conceived of their social presentation not only as an “opportunity to educate” (Stephanie) people about the condition, but also as a means of modeling self-acceptance. Nearly all of the contributors used the *in vivo* terms of “owning” or “rocking” their condition in order to dispel stigma. Natasha rejected the use of creams and makeup in order to demonstrate that she had personally destigmatized her condition:

> “I had times where my mom would suggest to buy like, not creams, but pretty much makeup to cover my spots. And then I thought in my head, ‘Well, that's not going to be helpful because . . . What message am I conveying? That this is bad?”

Natasha’s concern for the message she projected about her vitiligo surpassed social pressures to cover her condition. By displaying that she had accepted her skin, Natasha communicated to others that she had rejected the enacted stigma and transcended experiencing felt stigma related to her condition.

Other contributors shared this concern for how their public presentation influenced the public perception of their condition. Sophie noted how her tattoos helped project an air of confidence. In Sophie’s case, body modifications signaled bodily acceptance:

> “People obviously see my tattoos all the time and say, ‘Okay, nice tattoos!’ And one guy in the gym actually came up to me and said he thinks it's pretty cool that I'm like owning my skin and the way I look and that I'm not trying to cover it up.”

Sophie’s tattoo neutralized tension and operated as a site for public dialogue about her body. Among the various semiotic meanings projected by her body modifications, Sophie’s tattoos projected that she had accepted her body. Accordingly, this operated as a form of tension management, simultaneously relieving her from the communicative work of alleviating tension and permitting others to start conversation about her vitiligo.

Impression Management Strategies

As Goffman noted (1963), stigmatized individuals may develop “impression management” strategies to compensate for or conceal their stigmatized attributes. Contributors to this study employed “impression management” strategies in tandem with their body modifications to help them achieve their goals and overcome disadvantages. It is important to consider, however, that body modification and gender norms may add to the sensation of being on public display, as Sophie commented: “I think [attention from others] is like a combination of tattoos, white spots, and maybe that I’m a little more muscular than other girls are.” While body modifications and gender norms may gather undesired attention, they may also redirect the public gaze away from stigmatizing skin conditions and towards more socially advantageous features. Body modifications complemented and advanced “impression management” strategies contributors used to mitigate stigmatization.

The women who took part in this project detailed how their body modifications compensated for disadvantageous traits and steered the viewer’s attention towards more favorable aspects of their appearance. Lauren explained how the red color in her tattoo “kind of distracts from the other patches” of eczema she might have at the time, exemplifying Goffman’s (1963) concept of “covering” whereby the stigmatized individual reduces the stigma’s “obtrusiveness” to facilitate social activity (p. 102). Lauren commented that her tattoo functioned as “a way to kind of minimize how red [my eczema] is.” She expressed that her tattoo “shielded” and “distracted” viewers from her eczema, claiming, “When someone focuses on my body, it's not just like, well, that's a flare and so your eye will go there. It's like there's something else on it that is eye-catching, that I intentionally put there.” Lauren’s tattoo helped her manage impressions by attracting the viewer’s attention away from her eczema.

Similarly, Jacqui’s body piercing directed the viewer’s eye to more favorable bodily criteria. She shared how her nipple piercings boosted her confidence by compensating for parts of her body that she felt less comfortable exposing:

> “I think maybe the breast jewelry took the attention away from the scars . . . That’s something maybe that’s why I did flash my boobs so much is because I was, I was afraid of what was going on down below. Or I wasn’t so confident about what was going down on my abdomen. That maybe the breasts took the attention away.”

Jacqui’s piercings aided her “impression management” by highlighting favorable aspects of her body and luring attention away from her psoriasis and other markings of the skin. Since “the jewelry gets all the attention,” Jacqui felt empowered to manage her presentation. Body modification equipped contributors with the ability to control the impressions they project to others (Goffman, 1978).

Thrust into the spotlight of stigmatization, contributors utilized their body modifications to negotiate boundaries and define intimate relationships. Revealing and concealing certain tattoos allowed many contributors to calibrate the depth of their connections with others. While strangers may be able to view more public-facing tattoos, the bearer of the tattoo can limit the extent to which they share sentimental details and disclose the tattoo’s meaning. The process of “show and tell” helped contributors establish and define privacy and intimacy in their relationships. Since “not everybody can see” her tattoos, Natasha insisted, “It’s not like, ‘Hey, look at me, I got tattoos!’ . . . You have to be special. You have to notice . . . If I let you see it, then, hey, I'm comfortable enough for you to see it.” Natasha’s tattoos functioned as a gatekeeping mechanism that helped her manage bodily privacy and openness in her relationships. She discussed her process of gauging intimacy with new people in her life through her tattoos:

> “You don't know, you don't really know the real me. You don't know my real desires, my true essence and it’s told through my tattoos . . . I give a little bit of a sample, you know, it depends on if they're interested.”

In order for her to show and share her tattoos, Natasha noted, “I have to know you on another level before I really go deeper.” With people that she had not yet established a connection, Natasha could hide her tattoos. If she “were to want to get into a relationship with” someone, however, she might then say, “‘Well, this is, on the day that I got this tattoo my grandfather passed away . . . ’” As she formed deeper connection, she disclosed more about her tattoos: “It's going on another level.”

Considering that contributors to this study reported that their skin conditions often attracted undesirable attention, Natasha’s reflections suggest that tattoos may help individuals claim a sense of agency when negotiating privacy and openness in social interactions.

In describing the process of “impression management,” Goffman (1978) uses the metaphor of the theater. For individuals with skin conditions, body modifications can help direct their presentation as social actors by compensating for disadvantageous criteria and spotlighting more advantageous attributes. Meanwhile, body modifications can help individuals with skin conditions control the social stage by managing the cast of key players in their lives.

Goffman (1978) states, “the expressiveness of the individual appears to involve two radically different kinds of sign activity: the expression that he *gives*, and the expression that he *gives off* [emphasis added]" (p.2). Since individuals with skin condition often have little control over the expression that their stigmatizing conditions “give off,” body modifications can enable stigmatized individuals to “give off” other impressions that may complicate or complement the public presentation of their stigma.

The Polyphonic Body

Applying Bakhtin’s (1984) literary concept of “polyphony” to analyze contributor reports gives rise to an ambivalent, multivocal reading of the body and its physical attributes. Bakhtin (1984) employed the musical term “polyphony” to advance a literary theory that deprioritizes the author as the “monologic,” singular arbiter of reality. Instead, in Bakhtin’s “dialogic” analysis, the text and its various characters enunciate a “polyphonic,” or multi-voiced web of interacting perspectives and positions. As Belova (2010) notes,

> “the polyphonic narrative consisted of the relatively *independent*, in relation to the author, *voices* of characters, which developed *simultaneously, through intersection and clash* with each other, and endowed the novel with *unity* of an artistic and expressive *event*” (p. 70).

Applying this concept of “polyphony” to the body as text, skin conditions and tattoos engage in a multivocal dialogue that resists fixed, monologic delineations. On a fundamental level, modifying the body widens the possibility for polyphonic interpretations of the body. By wearing both a skin condition and a body modification, contributors incarnated a dialogic dynamic through their skin. Contributor tattoos and their skin conditions, therefore, multi-directionally interact across an array of personal, social, cultural, and commercial dimensions.

As the women who took part in this project illustrated, individuals with skin conditions may use their tattoos to signal a multiplicity of personal traits and group alignments. Tattoos displayed a range of images related to personal interests, fictional characters, personal connections, pop culture, and literary quotes. Meanwhile, their tattooed bodies displayed their membership in a variety of groups. While Stephanie displayed her involvement in a support group, Sophie wore tattoos related to each of her nuclear family members. Goffman (1963), however, suggests that the presentation of these group alignments may represent the experience of the stigmatized individual's ambivalent "oscillations of identification and association" with her "fellow-stigmatized" group of people (p. 107). By revealing and concealing different tattoos and skin conditions, affected individuals can traverse these oscillations, displaying both their alignment with and separation from various social groups. Through the lens of Goffman's (1963) analysis of in-group and out-group alignments, contributors used their tattoos to negotiate their connections with groups in and beyond their stigma. For example, Stephanie's alopecia ribbon tattoo functioned as a "stigma symbol" that visibly displayed the presence of her stigma. Meanwhile, this ribbon tattoo simultaneously operated as a "prestige symbol" that amplified her social capital amongst the members of her support group. Other tattoos on Stephanie's body, however, may functioned as "disidentifiers" that distanced her association with her alopecia by favoring her membership in other groups beyond her skin condition (Goffman, 1963, pp. 43-44). In signifying their multitudinous interests and group alignments, tattoos permitted contributors to strategically align and separate themselves from groups both within and beyond their skin condition, evoking a symphony of polyphonic social impressions.

Describing the multiplicity of meanings enunciated in communicative acts, narrative therapist Michael White (1991) remarked, "It is not possible to talk about anything without drawing out what it is not. Every expression of life is in relation to something else." White (1992) used the term 'absent but implicit' to identify this phenomenon within the therapeutic interviewing context. By applying White's (1992) concept to the analysis of this study's interview transcripts, contributors themselves appeared to reveal ambivalent relationships with their skin conditions. Notably, individuals wrestled to determine the extent to which their appearance defined their identity. Discounting the primacy of the skin as the defining aspect of identity appeared as a prevalent *in vivo* theme among contributors. Many of the women used the phrase "just skin" when describing their skin conditions, echoing Kayla's feelings that, "it matters a lot more who you are than what you look like." With a concern for the "absent but implicit," one might reasonably assume that contributors implied that more significant aspects than "just skin" cumulatively comprise one's identity. Conversely, contributors conveyed the importance of viewing their conditions as integral parts of themselves. Kayla noted that she had asked her friends about her vitiligo and they would claim not to notice her condition. In response, she felt unseen, remarking, "But it's just like, that's just me, you know?" Similarly, several of the women noted how their tattoos displayed their "real," authentic selves (Natasha). Contributors deprioritized the primacy of their appearance in favor of more character-based traits, while simultaneously acknowledging appearance as an influential aspect of identity. Ultimately, contributors appeared to suggest that they simultaneously *are* their skin, but are also *more* than "just skin." In doing so, they shirked stigma's monologic petrification of the self in favor of a more dynamic, polyphonic self-concept.

Body modification practices may destabilize the monologic reign of stigmatization over an affected individual's projected identity. Through the intentional selection and presentation of their body modifications, affected individuals can strategically toggle between various group alignments. In doing so, they construct multitudinous identities that transcend the confines of their stigmatized statuses. Meanwhile, body modification practices can offer polyphonic readings of the body that at once value the appearance of the skin and discredit the primacy of appearance as a defining aspect of one's identity. Through the multifaceted presentation of the body as a polyphonic text, individuals with skin conditions might skillfully capture and wield attention to satisfy an array of personal and professional objectives.

Body as Brand

Through the multiplicity of meanings projected through their skin condition and tattoos alongside the increased public attention, contributors constructed their identities in alignment with their individual personalities as well as their professional goals. Despite, or perhaps because of, the stigmatization and exotification of their vitiligo and tattoos, Sophie and Natasha both reported using their skin conditions in their physical training and modeling careers. By crafting their personal identities in tandem with their more public-oriented professional pursuits, Sophie and Natasha viewed their skin conditions and body modifications as essential features of their personal brands:

> "Dude, I'm not just a trainer, I'm a freaking brand. Like the way I look, the way I am. I'm a brand. I can literally use myself and I don't need anything else." (Sophie)

Sophie notably viewed her appearance as an asset that helped differentiate her in the fitness industry. Sharing the professional benefits of her appearance in her work as a personal trainer, Sophie noted how potential clients would often say, "Oh my gosh, you have tattoos. You have white spots. And you have an accent . . . Everybody wants to train with you." Sophie added that indeed, "they were right," recalling that her appointment book was "filled packed." Since her job as a personal trainer was "a lot about what you look like," Sophie experienced an increase in employment opportunities. Later in the interview, she additionally noted that she had also been interviewed by multiple magazines and had been featured in several fitness media outlets. For Sophie, vitiligo, tattoos, and her identity as a woman established a unique brand that anchored her work in the fitness and physical training landscape.

Natasha similarly utilized her appearance to advance her modeling career. She discussed how numerous photographers had taken an interest in her ever-changing body. As a result of her modeling work, Natasha had also received job opportunities as an actress for film projects. These professional engagements supported Natasha's process of dealing with stigma by invigorating the notion that her body was a work of art. She explained that "there are some people who stare and as for the people who stare," she would remind herself, "You are a work of art. You are a canvas. People are going to stare at beauty." In using her vitiligo and tattoos to progress her modeling work, Natasha inadvertently developed cognitive self-talk strategies for managing stigma from her condition.

Both Sophie and Natasha personally benefitted by functioning as group representatives for vitiligo and tattoos. Accordingly, they strongly expressed the importance of community representation in popular culture and media. Lamenting the lack of public visibility in the modeling industry, Natasha commented on how she knew photographers who would take pictures of "a woman with normal skin" that had falsely presented as having vitiligo spots. "If you really want to care about vitiligo," Natasha commented, "put a real person with vitiligo in your picture." She concluded with a statement that many contributors in their respective ways echoed throughout the study's interviews: "Authenticity is the key."

Conclusion

In consideration of the urge to be “authentic,” this study seeks to represent and amplify contributor voices and experiences with an attention not only to the challenges individuals with skin conditions confront, but also their strategic pathways towards agency. That said, the interview transcripts cumulatively display that a truly “authentic” experience that applies to all affected individuals may not exist. As evidenced by interview reports, however, individuals with skin conditions employ body modification practices to skillfully claim agency and construct their identities across medical, personal, and social lattices.

This study explored the relationships between body modifications and skin conditions with an attention to the construction of agentic identities amidst experiences of powerlessness, disenfranchisement, depersonalization, and stigmatization. Through the process of navigating medical treatment, individuals with skin conditions might incur various health-related costs and encounter multiple barriers to care. While many affected individuals develop concomitant health issues in tandem with their skin conditions, medical treatments generally fail to provide sufficient relief. In response, individuals with skin conditions may utilize body modification as a tool for the promotion of their holistic health and the management of their conditions. Since the appearance of skin conditions can fundamentally usurp one’s feelings of control over their body, affected individuals may struggle to incorporate their skin conditions as integrated facets of their identities. Meanwhile, the traumatic origins of many skin conditions may further complicate the fraught process of identity construction. To this end, body modification can facilitate individuals in seamlessly weaving their skin conditions with their sense of self. Extending beyond the realm of the personal, affected individuals may implement body modifications as they negotiate their social identities. Assisting the management of impressions and interpersonal pressures, body modification practices can function as de-stigmatization strategies. Furthermore, body modifications may offer distinct social benefits that support one's professional and aesthetic pursuits. Each of the contributors to this study displayed a range of strategies that transcended mere reactionary responses to stigma. Instead, their narratives illuminate how individuals with skin conditions develop multifaceted and multivocal identities that speak themselves into being "with the tongue of the body itself" (Bakhtin, 1984, p. 359).

Chapter 5. Discussion

This project sought to develop an understanding of the interpersonal and intrapersonal dynamics of body modification practices among individuals with skin conditions. More broadly, this study aimed to explore a dimension of the experience of skin markings that has been largely omitted from medical discourses. Having undergone numerous body modifications both before and after the onset of my vitiligo, I noted that my own tattoos and piercings therapeutically assisted me in making sense of my skin condition. In designing this study, I felt inspired to interrogate how aspects of my own experience might apply to other individuals with body modifications and markings of the skin. Most significantly, this research aspired to analyze how individuals with skin conditions identify with and create meaning from their body modifications. This study departs from many previous studies in that it offers methods by which individuals gain agency rather than merely cataloging the challenges that they confront. In engaging this primary question, I believe this study adds a valuable contribution to the existing body of literature on skin conditions, body modifications, and the construction of identity by examining their interactive relationships across a variety of social and personal domains.

This project found that individuals with skin conditions may use body modifications to gain agency in a wide range of contexts. By offering holistic support, body modifications may promote a sense of agency for individuals confronted with stubborn medical dilemmas. Body modifications may also encourage individuals to incorporate their skin conditions as an integrated aspect of their identity. Altering the body might additionally equip affected individuals with tools to manage stigma, gatekeep intimacy, and command attention. Addressing gaps in the state of research, this study highlights potential empowerment strategies and outlooks that body modification practices may give rise to in the lives of individuals with skin conditions.

Implications

Since skin conditions and body modification practices may draw out both compulsory and volitional changes to one’s identity, this research provokes an array of implications for medical, mental health, and social arenas. In an academic context, this study bears tensions between disparate conceptualizations of the embodied self, advancing a dialogic reading of the body as both a polyphonic text and a site for identity construction. It also enjoins previously separate areas of academic inquiry by exploring the relationships between skin conditions and body modification practices as qualitatively reported through contributors’ narrative responses.

Medical care professionals and mental health providers may benefit from observing how body modification practices might assist patients in treating and managing their skin conditions. Since many skin conditions develop as allegedly irreversible autoimmune illnesses and are also deprioritized as “cosmetic disfigurements,” most medical treatment protocols are widely regarded as ineffectual, impermanent, and potentially dangerous. While no permanent “cures” exist, most symptomatic treatments are generally considered ineffective. As a result, it might be useful for therapists and health care workers to explore how body modification practices can support patients positioned at the center of their own care. As individuals with skin conditions implement more holistic health regimens, body modification practices may promote patient quality of life and encourage affected individuals to become “happier humans” (Jacqui). For many medical providers, such as Kayla’s, “owning it” may function as the only viable medical option. Many contributors further noted that their body modifications operated as medical reminders that helped them reckon with the elusive nature of their skin conditions. In this regard, body modifications might assist affected individuals in dealing with the irreversibility of their conditions.

Tattoos may also operate as locations for community education surrounding skin conditions. In consideration of tattooing's educational dimensions, medical providers may consider tattoo subcultures as potential channels for public outreach and education campaigns. As several individuals used their tattoos as sites for public education, this study demonstrates a potential avenue for public health organizations, non-profits, and medical providers to consider when developing their programs. In this sense, tattoos may function as a potent thematic anchor for outreach campaigns that educate the wider general public and bring heightened visibility to a variety of stigmatized or underrepresented health conditions.

Although skin conditions are often portrayed as "cosmetic handicaps" that pose minimal threat to one's overall physical health, skin markings can cause significant psychological distress. While many skin conditions are stress-induced, markings of the skin may generate a range of stressors of their own. Stigmatization, social isolation, depression, suicidality, perseveration, obsession, fixation, and loss of bodily agency may accompany the appearance of skin conditions. That said, individuals with stress-induced skin conditions may enter a cycle of psychological unease exacerbated by the very stress it creates. In this study, all of the contributors reported that their skin conditions developed or advanced in tandem with traumatic events in their lives. The appearance of the skin condition itself, however, often appears to constitute its own traumatic experience. This study's findings offer mental health care providers insight into how body modification practices may operate as tools to alleviate this cycle of stress and improve affected individuals' mental and emotional wellbeing.

Contributors further explained how their skin conditions made them feel separated and divided from their own bodily processes. This study's findings indicate that body modification may support affected individuals as they incorporate their skin conditions as integrated aspects of themselves. Consequently, this study may help position body modification as an adjunctive therapeutic modality complementary to the work of mental health counselors, life coaches, social service professionals, and/or bodywork therapists. Many therapeutic interventions address mental health challenges through verbal processes, whereas body modification practices may support affected individuals through body-oriented means. More broadly, this study demonstrates the potential value of somatic practices in supporting body-mind integration and psychotherapeutic interventions.

This study may additionally educate artists and practitioners in the body modification industry about the experiences of their clients. Given the prevalence of skin conditions, tattooists, piercers, plastic surgeons, and other body modification professionals may regularly interact and work with clients who have one or more of the conditions explored in this study. By reviewing this study's findings, body modification practitioners may gain insight into the sensitive emotional undercurrents of their work. Clients may not willingly disclose the details of their complex relationships with their bodies. To this effect, this study may provide body modification practitioners a window into the lived experiences of their clients.

Considering the ways that body modifications supported de-stigmatization strategies among contributors, this study may offer individuals affected by skin conditions insight into the process of gaining agency in social contexts. Many contributors discussed their skin conditions and body modifications as potential assets that helped them advance their careers and professional pursuits. Deviating from previous studies, this project explores methods and perspectives that affected individuals develop to gain agency rather than merely recording the processes that made them feel disempowered. Accordingly, this study may offer individuals with skin conditions a variety of useful strategies related to intimacy negotiation, disclosure etiquette, impression management, personal branding, guerilla marketing, bodily acceptance, trauma-informed self-care, and incorporation. This wide range of strategies illuminates the diffuse influences of skin conditions and body modifications on an affected individual's life. While small in scope, this study attempted to constellate the interplay of these diverse contexts as they relate to the construction of identity, providing affected individuals with potentially confirmatory articulations of their own processes of identity actualization.

Limitations

This study conducted all of its one-on-one interviews through video chat sessions and phone calls. To an extent, this constraint may have forced contributors to verbally discuss their experiences, limiting the availability of body language and non-verbal communication. In effect, the phone and video interview formats may have enriched the verbal depth of the interview transcripts. Conducting each interview on the phone or through video chat appointments, however, may have discouraged discussions about physical attributes since these features were not readily visible to both parties during the interview process. Although this lack of visibility may have required contributors to verbally describe their conditions, it may have simultaneously concealed the subject from entering the conversation.

I also encountered significant challenges in recruiting eligible individuals in my local area. Since Facebook groups and Instagram then operated as my main means of recruitment, I received many inquiries of interest to participate. Although my online recruitment methods allowed me to reach beyond my local municipality, these methods simultaneously excluded individuals as a result of economic or place-based factors. Engagement on social media operated as a main avenue for recruitment. As a result, individuals who may not have had access to a computer or reliable internet bandwidth in their community had restricted opportunity to engage with the project. Compounding this issue, the majority of prospective participants who expressed interest in taking part in the study were non-US citizens living in the European Union. In order to comply with my university's IRB regulations, which asked to contain this study within the US, I had to decline interviews with many potential contributors.

While this project garnered wide international interest, the study's participants represent a limited data set. Seven one-hour long interviews examined the experiences of seven self-identified women. Five of these women self-identified as white, one woman self-identified as African-American, and one woman self-identified as Mexican-American. The age range examined in this study spanned from 20 to 48 years old. That said, this study's survey sample most predominantly represents the responses of individuals who self-identify as young, Caucasian women.

In contrast to representing a small demographic of age, gender, and ethnicity, the study displayed a significant variability between skin conditions and body modifications among participants. Each contributor had one of four different skin conditions: vitiligo, cystic acne, psoriasis, or eczema. Meanwhile, each individual identified more closely with three separate forms of body modification: tattoos, genital piercings, or plastic surgery. The limitations on both the uniformity of skin conditions and body modification practices resulted in widely different responses and experiences. While some of the nuances of individuals' experiences overlapped, there was considerable variation amongst contributor responses and experiences. Although plastic surgery technically operates as a body modification practice, it can involve a widely different set of social connotations and stigma cues than tattoos or piercings. Furthermore, psoriasis, as an autoimmune condition, appeared to generate more health-related concerns than cystic acne and eczema.

In an effort to gather an adequate sample size for this project, I decided to be more open with my eligibility criteria. That said, this study's findings present thematic generalizations drawn across far-flung experiential distances. Extending this metaphor of empty space, I suspect that many more "shadow stories" exist in the general public that remain absent from this study (De Medeiros, K., Rubinstein, R. L., 2015). When recruiting individuals to talk about their skin conditions and body modifications, the contributors had to self-elect their participation in the study. Many of the contributors who self-elected to take part in this study had already exhibited comfort and facility with serving as public-facing representatives for their skin conditions. Furthermore, my recruitment methods required participants to consent to allow me to share excerpts of the interviews and images of their bodies with the public. Consequently, this may have further skewed the data both in the individuals who elected to share their stories and the selection of stories they chose to share with a wider audience. As contributors discussed their experiences in conversation with me, they were simultaneously broadcasting their conversation with the general public. This encroachment of intimacy may have misrepresented the primacy of certain themes and disproportionately favored various topics for the sake of education and advocacy. That said, individuals who felt uncomfortable discussing their skin conditions may have felt disinclined from participating in the study. Other individuals who felt embarrassment, shame, or pain in relation to their body modifications may have also decided not to participate. As this research suggests, the experience of having body modifications often derives its power through the ability to establish boundaries of intimacy and disclosure. Some individuals, then, may enjoy the privacy and sense of empowerment they feel from keeping their body modifications hidden.

Future Directions

This research study illuminated some of the commonalities evinced across a wide range of skin conditions and body modification practices. In the future, however, researchers might narrow their focus to explore the nuances of one type or set of skin conditions at a time. To this effect, it might be useful to delineate skin conditions with purportedly “autoimmune” origins from other more benign markings of the skin. “Autoimmune” conditions seem to categorically differ from other markings of the skin, since they often develop in tandem with other diseases, may indicate graver health concerns, and often require more conscientious treatment protocols. Additionally, autoimmune conditions often develop after birth and early adulthood. This developmental aspect appears to influence narratives of redemption and reclaiming bodily agency. While the external stigmatization between certain markings of the skin may seem uniform, this study revealed the nuances presented with different types of skin conditions. The process of bodily acceptance and incorporation appears to differ across individuals who develop the skin condition at birth versus those who experience their skin condition as the byproduct of a chronic health issue. Some skin conditions may also elicit varied social responses. While conditions such as vitiligo have been exotified in popular media, other conditions garner more contagion-related stigmatization. For example, the scaly red skin markings associated with psoriasis may appear to be more contagious than the universal baldness found in alopecia.

Furthermore, researchers surveying this topic should investigate alternate data collection methods. Participant observation could be employed at vitiligo conferences or tattoo conventions. Since impression management comprised a key theme in this study, researchers might also examine the influence of body modification practices upon the interpersonal relationships with significant others of people with skin conditions. Racial concerns also appeared to be an important theme for the one African American contributor to this study.

Further studies that explore the influence of race and stigma on the experience of individuals with skin conditions may display new insights into the construction of racial identity. Similarly, this study only analyzed the experience of women and a deeper exploration of the experiences of men, non-binary, transgender, and/or genderqueer individuals could offer valuable insight into the relationship between body modification, illness, gender, and identity.

Digital Storytelling

The second phase of this research study seeks to create a digital storytelling presentation as both a research product and interpretive process. Extending the study design's emphasis upon narrative interviewing and analysis, I aimed to present my findings alongside my self-reflexive situatedness with the subject matter. The development of this presentation interrogates my role as both a researcher collecting participant stories and a human being working through my own narrative understandings of having a skin condition and body modifications.

I further considered how individuals with skin conditions and body modifications encounter stigmatization, laden with social messages about normative appearance and beauty standards. In developing the foundation for this digital storytelling presentation, however, I aimed to engage the women's voices and deconstruct essentialized notions of beauty. Many individuals with skin conditions have been addressed as having a "cosmetic handicap, disfigurement, or impairment" (Kent 2000, p. 118; Porter 1991, p. 197). This digital storytelling process aspired to undo those labels and offer contributors and myself greater autonomy in self-presentation (Fiddian-Green et al., 2019). I additionally sent follow-up emails to ask contributors if there were particular segments of the recordings that they wanted to include or omit. As the interviews concluded, I also began asking contributors to select the essential components of their stories that they hoped "would not be left out" in retelling their stories. This collaborative invitation helped guide my selection and editing process. That said, I aspired to ensure that individual participant voices and perspectives were honored for their uniqueness and idiosyncrasy. While the coding for this research project sought to organize the themes into commonly shared categories, the digital storytelling arm of the project hopes to illuminate more of the experiential nuances among contributors.

A key feature of this study's digital storytelling component is that the final products will be shared publicly. Since this study explored how media representations and stigmatization impacted individuals with skin conditions and body modifications, I intend to distribute and share this digital storytelling project publicly to present a previously untold, collaborative narrative telling of contributor experiences (Wood, Fredericks, Neate, & Unghango, 2015). Although the academy has historically labeled individuals with skin conditions in ways that may stigmatize their lived experiences, the digital storytelling aspect of this study seeks to re-position contributors as narrative co-performers within the body of research findings.

Research Reflections

"Let everything happen to you: beauty and terror.
Just keep going. No feeling is final."
- Rainer Maria Rilke

Every contributor to this study remarked how they hoped that their participation in this project might help someone in a similar circumstance. Little did they realize that the first person they would help would be me, the researcher hitting the record button and asking them to divulge intimate details about their lives. This thesis project has been nothing short of an academic exorcism for me. In designing this study, I sought to investigate whether dimensions of my own experiences with chronic illness applied to other individuals with skin conditions. Although I functioned as the researcher in this study, I underwent a deep process of self-interrogation and internal dialogue. On more than one occasion, I had to stop my own self-interview and simply cut the tape. Like many of the contributors to this study, my skin condition shares its origin story with other deeply painful stories of personal trauma. Reflecting on my own challenges with giving language to these experiences, this research process has deepened my appreciation for each and every contributor to this study and their willingness to unearth and share their journeys with an inspiring compassion for others.

While I was in the process of conducting this research, I discovered worrisome medical information about my state of health that spiked my anxiety and sent me to the brink of a mental breakdown. Additionally, the world began experiencing the COVID-19 global pandemic throughout the course of the project. This backdrop of widespread medical doom featured as a continual reminder of my complicated state of health. In hearing each contributor's remarkable story, however, I felt a mixture of hope, encouragement, and trust in the triumph of the human spirit. This study has further helped me to reposition and de-personalize my own individual health challenges in acknowledgment of a Buddhistic understanding of the universality of suffering. I have been struggling to manage multiple chronic illnesses for over five years and resonate with the medical exhaustion each of the contributors discussed.

Admittedly, my medical journey departs from the contributors to this study in that I have never used Western, allopathic medicine for treatment and have entirely avoided pharmaceutical prescriptions for my health issues. Instead, I have been addressing my health challenges through a fruitarian diet, herbal protocols, long-term fasting, and a variety of shamanic ceremonies from indigenous medicine traditions throughout North and South America. Completing this project offered me a window into the Western medical course of treatment as I determine the next steps of my own medical journey. To be transparent, at the conclusion of this study, I remain skeptical of the Western medical model and continue to lean towards herbal and shamanic healing traditions. That said, this study repeatedly challenged me to evaluate my biases towards health promotion and self-care, while repeatedly forcing me to confront the gravity of my own suffering, as well as my own healing. Through wrestling with these themes, this study affirmed for me that “owning” my skin condition, my state of health, and the body I inhabit may be more than just the spoonful of sugar that helps the medicine go down.

This project has also helped me to explore my professional goals and artistic dreams. Before entering graduate study, I had to decide between two options: (1) attend graduate school; (2) take the rare opportunity to undergo a tattoo apprenticeship. Since my apprenticeship offer would remain waiting for me, but my graduate school offer would not, I decided to advance my education. Unexpectedly, my graduate school experience has allowed me to ask deeper questions of tattooing, not only as a potential career path, but also as a deeply spiritual, ritual, and symbolic practice performed by humans for as long as recorded history. This study has been a platform for me to explore tattooing through an academic lens and to understand the value of tattoos in the life journeys of individuals who may have troubled relationships with their bodies. As a result, my artistic interests have shifted from representational art and have moved more towards tribal tattoo traditions that mark the body with a deeper consideration of the body’s natural movements and anatomical flow. This study has helped me to view the body as a dynamic, breathing canvas as opposed to a flat surface for the application of static images. The project’s findings related to incorporation have powerfully shaped the way I approach and appreciate tattoos that honor and complement the body's movement in space.

Similarly, this project operated as a means for me to develop a better understanding of my professional interest in narrative therapy. In preparation for this project, I completed an Introduction to Narrative Therapy workshop through the Evanston Family Therapy Center with narrative therapists Jill Freedman and Gene Combs. I regularly consulted narrative therapy techniques and concepts to design my questions and follow-up prompts, as well as to analyze the research data (see for example Denborough's *Retelling the Stories of Our Lives: Everyday Narrative Therapy to Draw Inspiration and Transform Experience*, 2014; and White's *Maps of Narrative Practice*, 2007). My acquired understanding of therapeutic techniques helped me to elicit contributor responses and engage deeper questions. When applicable, these techniques also permitted me to more confidently challenge and reframe contributor responses.

While this study focused on the effects of stigmatization, I felt that the concept of stigmatization often portrayed contributors as victims of subjugation. Although contributors unanimously discussed the significant influence of stigmatization on their lives, I felt as if my questions had mistakenly conceptualized stigmatization as an overly central factor in the lives of individuals with skin conditions. In contrast, many contributors sought to discuss other topics beyond their social challenges ranging from intimate relationships with new partners to the nuances of their modeling careers. Throughout the research process, I found that the language of stigma employed by Goffman (1963) appeared to label contributors as "stigmatized" and "abnormal." My research questions consequently appeared to reinforce harmful labels that affected individuals may already experience. Conversely, many of the contributors regarded their skin conditions as social assets and professional tools. By weighting my questions towards stigma-related subjects, I also struggled to organically build upon conversational threads that tangentially arose from the interviews. In future directions of this study, I would like to create more opportunities for exploring a different range of topics with contributors, particularly in relation to the concepts of incorporation and bodily identity integration.

This study challenged me to self-reflexively examine my own projections and assumptions about skin conditions and body modifications. The first interview was largely informed by my own predispositions, but grounded theory helped me pivot after each interview to rephrase certain questions and interrogate emergent themes. Despite using the data to inform my research questions, I still struggled to appropriately incorporate my own journey into the interviews. I noticed that once I began sharing my own personal insights and experiences, the contributors seemed to be more open to disclose information about their lives. That said, I grappled with navigating my inclusion in the study. Although my personal story helped to build rapport with participants, I did not want to upstage the women’s responses. Perhaps, even now, I continue to repeatedly re-locate my situatedness in this project.

Interviewing other people with vitiligo offered poignant insights, but may have prevented new understandings from emerging out of the data. Oftentimes, a participant would answer my question before I had the opportunity to ask it. As a result, I often found myself inserting questions into my interview guide in order to develop or diminish certain themes that I discovered in my coding. That said, my coding carried a lot of my personal projections about the meaning of skin conditions and their effects on people’s lives. Additionally, my first interview surprised me. I did not anticipate that my participant would largely bypass discussing her tattoos and instead focus more on her genital and nipple piercings. I found myself struggling to manage this interview, balancing both my position as a male researcher, while also discovering that the contributor wished to discuss a theme that was not featured in my research questions. In hindsight, I could have better prepared for the unexpected and allowed the interviewee to speak more as a human than as mere data for my study.

Furthermore, I discovered that many of my responses as an interviewer felt canned and inauthentic. Sometimes I displayed exemplary active listening by mirroring some of the contributors' statements back to them. Other times, however, I fell into patterns of repeatedly using the word "interesting." When reviewing through the transcripts, I discovered that the repeated usage of this word seemed to position me as a researcher more interested in the data he was culling from the interview than the conversation with the human being sitting in front of him. That said, in my future work, I hope to be more present in the moment with my participants and engage in active listening.

In a sense, the second interview demonstrated some of the lessons I had learned from the first. After signing the informed consent document and arranging to have an interview with me, my second participant explained that she did not have any tattoos or body piercings. After a moment of discussion, I realized that she had undergone plastic surgery. We then completed the interview with an attention to plastic surgery as a body modification practice. Despite not fitting my initial areas of focus for the project, this interview offered a unique perspective into the variety of motivations and articulations of body modification practices. While the themes between the first and second interview were very hard to organize, I discovered a surprising number of overlaps. If granted the opportunity to do this study a second time, however, I would put more effort into recruiting early and engaging local participants in order to promote stronger commonalities amongst my transcripts and interviews.

In designing this study, I challenged myself to explore my own personal relationship to my skin. Before this past year, I had not allowed anyone to take a photo of me for several years because of my vitiligo. As I composed this study, however, I challenged my body-confidence issues to speculate whether this aversion towards the camera might be transformed into a cathartic or meaningful experience for my contributors. The various strategies contributors employed to manage stigma have further informed my interest in digital storytelling for this project's future developments.

I enjoyed the process of adopting a narrative approach to my data analysis. My first interview was coded several times over. Searching for narrative sequences, turning points, and contamination and redemption narratives inspired me to examine not only the in vivo terms, but also the wider story arc of the individual's response. That said, this became much less useful as my participants represented such widely dispersed demographics. This study would have benefitted from recruiting a narrower set of participants with more commonalities.

While I do feel that this study answered my research questions, I also felt personally excited to find so many shared experiences between my own life and the contributors to my study. Although my own healing process sometimes inhibited me from being responsive to the needs and directions of my participants, I feel that my position in this research provided the study with useful insight. To be clear, I believe that undergoing my own process of healing and sense-making while simultaneously completing this study operated as a vital reservoir of inquiry and resource for analysis. In talking to my participants, I discovered that having a skin condition can be a profoundly nuanced and unique experience. At the same time, this project has felt like a homecoming of sorts for me. Each of the contributors to this study helped to alleviate the isolation and alienation accompanied by my vitiligo. In concluding this project, I feel nourished by a community of support formed by people who willingly shared their life stories, their vulnerabilities, fears, traumas, hopes, laughter, tears, and compassion for the “person out there” who this project might help.

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APPENDICES

Appendix A: Contributor Characteristics and Demographics

Characteristic/Demographic		***Number of Contributors***
Type of skin condition	Vitiligo	3
	Alopecia areata	1
	Psoriasis	1
	Eczema	1
	Cystic Acne	1
Type of body modification	Tattoo(s)	6
	Body Piercing(s)	2
	Plastic Surgery	1
Appearance of skin condition	Large area of the body	5
	Small area of the body	2
Race of contributor	White	5
	Black	1
	Latinx	1
Age of contributor	20-25 years old	1
	25-30 years old	2
	30-35 years old	2
	35-40 years old	1
	45-50 years old	1
Phone or video interview	Phone Interview	2
	Video Interview	5
Years since diagnosis	0- 5 years	1
	10-15 years	3
	15-20 years	2
	30-35 years	1

Appendix B: Interview Schedule

In this study, I seek to ask several main questions, followed by possible prompts intended to deepen more nuanced understanding:

Interview Questions

1.) In some discussions about body modification, people mention that their tattoos offer them a sense of protection or safety in some way, while others don't feel their tattoos do this for them. What has your experience been?

- (As applicable) Have you ever felt like your tattoo / body modification has offered you protection from criticism or distracted others from making fun of your skin?

    - Possible Follow-up Prompts:
        - Can you give an example of a time when you felt this way?

        - What did you make of that?

2.) Some people with skin conditions report feeling a loss of agency or control over their appearance, while others don't identify in this way. What do you think?

- (As applicable) Does this feeling of losing control over your body apply to your experience or no? Do you think your body modification has influenced this for you?

    - Possible Follow-up Prompts:
        - In what ways?
        - Has this feeling changed over time for you?
        - How so?

3.) How has your tattoo / body modification impacted how you feel about your appearance?

- (As applicable) Earlier you mentioned that your skin condition made you feel different than everybody else. What is it that makes you feel different?
    - Do you feel your tattoo/body modification also makes you feel "different"?
    - Do you feel "different" in a different way?

    - Possible Follow-up Prompts:
        - Can you give an example of a time that you felt different because of your skin condition?
        - Can you give an example of a time when you felt this way because of your tattoo?
        - What did you make of that?

4.) In your opinion, do you think getting a body modification is an important part of body acceptance for people?

- Possible Follow-up Prompts:
    - In what ways?
    - How so?

Possible Rapport-Building Questions about Skin Conditions:

- Can you tell me a little bit about your skin condition and how it developed?
- Is your skin condition actively spreading and changing?
- How have these changes affected the way you have felt about your body? In what ways? Can you give an example?
- Do you feel differently about your body now than you used to? How so? Can you give an example of then and now?
- Do you feel like your skin condition has affected how other people see you?
- How so?
- Has someone ever made you feel uncomfortable in your skin?
- Can you describe that experience?
- How did that make you feel?

Possible Rapport-Building Questions about Body Modifications:

- How did you decide where to put your tattoo / body modification?
- What appealed to you about having your tattoo / body modification on this location of your body?
- Were you trying to conceal or coverup your skin condition from showing?

- Do you have more than one tattoo?
- Do any of your other tattoos / body modifications function differently for you?
- How do your body modifications make you feel about your body?

- What do you enjoy or dislike about the aesthetic of your body modification?
- Do you think your body modification has helped you to feel differently about your body?
- In what ways?

Concluding Question about Contributor Experiences:

- If someone were to share your story, what would you want to make sure that they don’t leave out?

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