Vitiligo: Race and Gender in the U.S. Proposal

**Abstract:**

Vitiligo is a skin condition, which can happen to anyone. This is caused by depigmentation, like albinism. From a medical standpoint, it is a harmless condition but has vast social and cultural impact. People who develop Vitiligo do not exactly know what it is when they first get it; their initial thought is that the little white patch is a blemish, which will fade away. However, when it starts to spread thus covering various parts of the body, individuals panic and become confused as to what is happening to them. Furthermore, because changes in skin color are notable, people with Vitiligo face stigma and ostracization from family, friends, and community. In the study, I aim to find how individuals with Vitiligo in the U.S. go through daily life, overcome stigma they are subjected to and ostracization that comes with the condition.

**Background:**

I will examine two examples from the contemporary pop culture in the U.S. to see how ideas towards this condition may have changed over time. However, I believe this analysis would be stronger with first-hand data, and I am requesting Bigel support to assist me with this work. There is very little research done on the social and cultural impact of pigment-altering diseases and even less specifically about Vitiligo. There are several different medical conditions that affect skin pigmentation and thus impact people's racial identity or how their identity vis a vis race is perceived by others (see Macy 2016 discussion of Albinism; see Findlay 2017 discussion of Ichthyosis "red pigmentation" and race). Porter and Beuf (1991); found that black individuals with Vitiligo are more severely affected by stigma, than their white counterparts. It has been hypothesized that high levels of perceived stigma could be related to distress, the importance placed on a cure, labeling Vitiligo as disability, and the visibility of the depigmentation. Cultural reaction to Vitiligo has changed over time, as seen with Michael Jackson to Winnie Harlow. With this said, there is stigma surrounding depigmentation that impacts people such as Albinism. Albinism has been stigmatized by Africans and African Americans, where they were taken as sideshow acts and in Africa people with Albinism are hunted because they are thought to possess magical powers. Cultural attitudes have changed about this and similar conditions over time in the U.S., from the early 1900s when people were stared at as "freaks" and recruited into circus sideshows (Macy, 2016), to more contemporary times where celebrities are "out" about it. With Ichthyosis, a congenital severe, rare, and painful skin condition that makes individuals skin red and scaly are faced by stigma, individuals are often associated with rude nicknames like "traffic light" and "red head match"(Findlay, 2017), alongside struggling with associating themselves with they race they identify as. The "king of pop", Michael Jackson, claimed he developed Vitiligo, but was accused of using skin bleaching products, which was combined with multiple plastic surgeries that changed his features thus suggested that he wanted to look less like himself, and wanted to "look white"(Wyman, 2012). Through these actions, the larger society started to label him as trying to be ‘white'. In 2016, the Canadian-born​ ​model​ ​named​ ​Winnie​ ​Harlow​ ​has​ ​graced the​ ​billboards​ while​ ​embracing​ ​her​ ​Vitiligo​ ​and​ ​speaking​ ​up​ ​about​ ​it.​ ​Through​ ​her​ ​actions, ​she​ ​is challenging​ ​the​ ​norms​ ​of​ ​beauty​ ​and​ ​shutting​ ​down​ ​the​ ​stereotypes​ ​people​ ​have​ ​about ​Vitiligo and related conditions. Harlow is stepping forth and talking about her childhood with Vitiligo and how this has shaped her, she talks about how she was bullied and called a cow (Whitelock, 2014). She is changing the norms by bringing awareness to what Vitiligo is by not covering it up with makeup and bring forth the kinds of stigma people with this condition face (Goffman, 1963). For my original research, I would like to interview everyday/nonfamous people to see how they are living with the condition and the kinds of stigma they experience as a result.

**Nature of the Problem:**

The stigmas that ​arises in communities which leads to ​rejection​, bullying, and​ ​fear​ ​of people​ ​with​ ​Vitiligo, thus causing problems as to how individuals with this condition see themselves, their "self worth" and the impacts the condition has on their self-esteem, which relates to body image, sexuality, attractiveness, or finding partners. Therefore ​resulting​ ​in​ ​individuals​ being​ ​ostracized​ ​by​ ​their ​community, friends, and family.​ ​In​ ​the studies done on Vitiligo, ​people​ ​have​ ​been​ ​stigmatized​ ​and​ ​ostracized and thus seek ways to​ ​cope​ ​with​ ​their​ ​conditions where they turn towards​ ​treatments,​ ​spiritual​ ​help​, or​ ​self-harm. With this study, I can understand​ ​how​ ​people​ ​in​ ​the​ ​U.S.​ ​react​ ​to​ ​Vitiligo​ and how the​ ​communities treat or accept individuals with this condition.​

**Existing Research:**

There are not many studies on the topic of Vitiligo from an anthropological perspective. Although, there is more of research done in biomedical perspective (Shah & Bonita 2014; Suman & Shyam 2011; Judith & Ann 1991). Another restriction is that the research mainly consists of data from children with (e.g., how the children are treated for this condition and the stigma that prompts the family to look for treatment). With that said, the existing studies on Vitiligo come from countries such as India or Saudi Arabia (Shah & Bonita; 2014). Besides having limited data from a few countries, there is not much data on how the culture reacts to Vitiligo and the stigma individuals encounter in their daily lives. Due to lack of understanding about the condition, people tend to avoid individuals with Vitiligo in fear of contracting the condition, even though it is not contagious (National Institute of Arthritis and Musculoskeletal and Skin Diseases; 2014). Due to this, individuals with Vitiligo have to cover themselves up with makeup, layer of clothes or refuse to go outside in fear of being stared at or questioned. Therefore, this expanded research aims to understand the challenges faced by people with Vitiligo, especially, since there are not many accounts in Anthropology.

**Methodology:**

 In my research project, I will aim to address the issues of adults with Vitiligo, finding out the U.S. cultural reaction to Vitiligo: from individuals with the condition, what they have noticed and how they are treated. I plan to qualitatively interview ten adults with the condition in the U.S., who I will recruit from an organization called VitFriends. Recruitment strategy is that I will attend meetings at the organization, where I will do in-person recruitment, ask them if they would like to participate in the study. From here, I will perform individual interviews and utilize photovoice and journals.

For this research, I plan to use individual interviews, with journals and photovoice as an interview prompting strategy. I will ask them to take pictures of their experiences and how they view their Vitiligo. With this said, I will be conducting multiple interviews with the use of the pictures the participants will take, in order to get information about the condition from the individual's perspective. This will document what stigma they experience and the larger cultural perspective of them in terms of gender and beauty, wanting to fit in, the possibility for intimate relationships, and how they see themselves and their life goals (like marriageability, building a family, etc). I am particularly interested in how gender impacts individuals with Vitiligo[[1]](#footnote-1). Additionally, I am interested in the way this condition insects with race and ethnicity, given the prominent cases of pigment loss for African Americans (Michael Jackson and Winnie Harlow). The multiple individual interviews assists in understanding what the participants feel, see, and face on a daily basis. Though journals and photos, I will be able to learn more of how the participants feel and the effects of Vitiligo and people's response to it. Before conducting interviews, participants will fill out the questionnaire on an online platform to gather demographic information.

For my recruitment strategy, I will be reaching out to the Vitiligo organization known as VitFriends, which is a support group. From this organization, the sample will consist of ten adult participants, who will be divided into five women and five men of working age. There are no restrictions on when the participants had developed Vitiligo, but I will analyze information from different age groups on how their experience varies due to when they had developed Vitiligo. From the participants, I will ask questions on their experience with the condition, how they are viewed by the culture, treatment they might have received, and coping mechanisms for Vitiligo. This will be used to help develop advocacy materials.

While people may be initially reticent to speak with me about this issue, I have several approaches to help build rapport and get them to open up. First, I will demonstrate that I am empathetic to their concerns because I have first-hand experience through family members with this condition. Second, I will respect the interviewee but would probe to find out why they do not feel comfortable talking about it, consequently, gaining information as to why people would not feel comfortable talking about this subject or question. I am interested in why people are and aren't comfortable talking about it, men or women, if there is a specific age group, and/or experience they had. Furthermore, for those who are reticent to talk, they can participate by sharing their stories visually (through PhotoVoice) and/or through journals. Through my research, I will get an understanding of the stigma individuals might face.

**Pilot Research:**

This Bigel project would build upon some pilot work that I began for Research Methods class (Anth 301), where I conducted an interview with Patricia, a representative from VitFriends, who explained that Vitiligo is not taken seriously, due to it not affecting many people, even though it can happen to anyone. There are cases of individuals committing suicide, but this is dismissed because there is not a high rate. Consequently, I argue that Vitiligo is viewed as a condition that is not serious and often dismissed as unimportant, despite the very serious social and cultural consequences that accompany the disease. Accordingly, the proposed study takes into consideration the individuals who are stigmatized and the culture's reaction to this skin condition where depigmentation takes place. From my pilot interviews, the interviewees mentioned the most important issues were about how to hide their Vitiligo to reduce stigma and how to "be strong" so stigma did not impact them. Through the pilot interviews, I was able to gain insight into how individuals with Vitiligo felt when they first developed this condition to how they feel now, the treatment they received, and how people treated them.

**Conclusion:**

Consequently, in this research, I will be able to show how in the American culture's views of Vitiligo may have changed from the time when Michael Jackson had developed it to now. The anticipated project will also address the struggles, stigma, understanding the conditions and challenges that come with Vitiligo, and how people around these individuals react to the disease, even in contemporary times. In addition, I am interested in how people who develop Vitiligo later in life go through the transition of accepting and being accepted with the condition. Alongside this, I am interested in learning about the race and gender dynamics of who how stigma contributes to daily life.

**Grant outcome:**

Upon completion of the research, I will give a presentation about the work I conducted to the department and provide a one page summary for the website. Ideally, I would like to get this study published so this information may help give an understanding about the stigma, ostracization faced from family, friends, and the community, and its effects on individuals.

 **Budget:** I am requesting the full amount of the Bigel application of $2500,00. This will allow me to do the maximum amount of work possible. The funds will be spent accordingly:

* Travel to and from NYC and parking: $1312
	+ 41 trips (multiple interviews with 10 participants) x $12 each for tolls = $492
	+ 41 trips x $20 each for parking = $820
* $12/hr working 40hrs per week for 2 months: $3840
	+ $12/hour x 40 hours/week = $480/week
	+ $480/week x 8 weeks = $3840
* “Pizza party” for support group participants at end: $200
* Journals/pens for participants: $55
* Survey on an online platform: $26

Total: $5433
Note: the total expenditures for the proposed research exceed the limit available via the Bigel grant, thus I ask the Grant Committee to be as generous as possible and fund me with the full award.

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1. From my pilot interview with Patricia from VitFriends, she had informed me about how there is a gender dynamic were men do not tend to talk about the struggles they face with their Vitiligo. Due to this, they tend to cover their Vitiligo up with make-up. While women are a little more open to discuss their experience. This dynamic is present, due to the stigma that men can not be emotional. [↑](#footnote-ref-1)