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Content Analysis of Vitiligo Portrayal on Social Media

By

Mary Catherine Miller

A thesis submitted to the faculty of The University of Mississippi in partial fulfillment of the requirements of the Sally McDonnell Barksdale Honors College

Oxford

May 2022

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ACKNOWLEDGEMENTS

I would like to give my greatest appreciation and gratitude to my advisor, Dr. Erin Holmes. This project has been in the making since my freshman year honors 102 class with Dr. Holmes. Her continued support throughout my undergraduate career has helped make this novel research I am so passionate about possible.

Secondly, I would like to thank my committee members Dr. Meagan Rosenthal and Dr. Marie Barnard for their valuable input with reviewing and advising my writing. I would also like to thank Anita Osuri, for her assistance with data collection and her enthusiasm for the project.

Next, I would like to thank the Sally McDonnell Barksdale Honors College for providing me with the opportunity to make this research possible. Over the past four years, I have gained many friendships through peers and faculty that will last a lifetime.

I would also like to thank my family and friends for their continued support during my academic endeavors. Their love and encouragement have enabled me to not lose, but further ignite the passion for my thesis.

ABSTRACT

Given that vitiligo affects a small percentage of the world population, and its affects are not widely known, there is an increasing need to learn of its effects on those with vitiligo, both physical and psychological. Social media has become an influential platform to spread awareness and build confidence in those with vitiligo. This study aims to find how vitiligo is portrayed through social media using content analysis procedures. This is a cross-sectional content analysis that utilized a codebook to analyze Instagram posts. The results were analyzed by interrater reliability and frequency for each coder. The findings of this content analysis show a wide range for interrater reliability based on objective and subjective categories. The variable frequencies showed that most of the posts were of younger white females with moderate amounts of clothing and varying degrees of strength of contrast over a small area and varying amount of body shown in the posts. Future research should employ alternative data collection methods, such as in-depth interviews, to understand study variables at a deeper level. Additionally, pharmacists should be aware and educated about mental illness and other comorbid conditions associated with vitiligo diagnoses.

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INTRODUCTION

An Introduction to Vitiligo

Vitiligo is a disease that affects “the largest body organ,” the skin, “and other vital systems” through the loss of natural skin pigmentation (VR Foundation, a). Melanocytes, “pigment-forming cells” are damaged or destroyed, leaving behind white patches along the skin of those affected (Stöppler). Although there is ongoing research on the exact causes of vitiligo, it is known that there are physical and psychological triggers that induce vitiligo. “Psychological stress... severe sunburn... [and] prolonged contact with certain chemicals” are events that can trigger vitiligo’s appearance (VR Foundation, a). Vitiligo is also hereditary and can be classified as an autoimmune disease. The trigger event “creates stress” in the melanocytes and an “over-reactive immune system mistakenly identifies these stressed-out cells as intruders” (VR Foundation, a). This leads immune specialized T-cells to attack the intruder, which drives “progressive skin depigmentation” (VR Foundation, a).

Although vitiligo only affects “between 0.5 percent and 1 percent of the population worldwide,” there are a variety of people who have the skin disease (Vitiligo: Medlineplus Genetics). A majority of those diagnosed with vitiligo have darker skin tones, which makes the loss of pigmentation more prominent and thus, easier to diagnose. Regardless of skin tone, vitiligo can cause a lasting “psychological burden” as well as “social anxiety,” “embarrassment” and “shame” for anyone who is affected (Bidaki, Reza, et al., Salman et al., Porter). These side effects create a significantly harsher environment for the small percentage of the population who have vitiligo online and

offline. Because of these psychological effects, some people with vitiligo will “apply excessive amounts” of makeup and “wear long sleeves” and other covered clothing, even during the heat, in order to make sure their skin remains hidden (Porter).

Social Media and Vitiligo

Social media has become an influential platform in bringing awareness to the public about vitiligo and positive encouragement to those who have vitiligo. There are many support groups and blogs that enable those with vitiligo to become more comfortable in their skin. Vitiligo Society has a website and online publication, *Vit Life*, that motivates those to be confident with themselves through posting personal experiences of those with vitiligo. The people included in the article tell how they transitioned from constantly covering their skin from others to showing their skin online. More recently, there has been a “surge in people opening up about life with vitiligo online,” which has inspired others to go public with their true skin (Page). Brigata used to “photoshop her pictures” and “pretend she didn’t have” vitiligo until she “didn’t want to live in fear anymore” and began sharing her story on Instagram and YouTube (Page). It took some time for Brigata to grow accustomed to the positive feedback she received from followers and supporters, but now she ‘feels better’ not hiding her vitiligo and encourages others with vitiligo to not let ‘vitiligo stop you from living life to your fullest’ (Page).

Many well-known fashion brands have signed models with vitiligo, which has increased the positive push toward those with vitiligo to embrace their natural beauty without trying to cover their skin.

There are quite a few celebrities who have vitiligo, but the most well-known is model Winnie Harlow. She was a contestant on America's Next Top Model and has since modeled for the Victoria's Secret Fashion Show, Tommy Hilfiger and Steve Madden. She has recently appeared on several magazine covers and runways. Harlow is known for spreading confidence and empowering those to choose their own beauty standards instead of determining their beauty on what others claim. Harlow presented a TedxTeen Talk "How I Define Beauty". Closing the TedxTeen Talk, Harlow leaves the audience with advice to "be your own person" by knowing "what beauty is" to you "rather than looking to a magazine or to even me for what beauty is" (Harlow). Most importantly to "know it in your heart, and make your own mold for what beauty is" (Harlow). Devontae Shuler has vitiligo and was a guard for the Ole Miss basketball team. He has brought awareness to the Ole Miss community with his position on the team. He has grown from attempting to hide his skin to becoming "comfortable" in his "own skin and proud of who" he is (Ole Miss Athletics). After a basketball game, a fan with vitiligo came up to Shuler and they talked and took a picture together. Shuler uses Vitiligo Day to spread awareness and encourage those with vitiligo to be comfortable in their own skin.

Camille Ivy has had vitiligo since she was four years old, and now in her twenties she doesn't let vitiligo slow her down. She was a member of the University of Mississippi Pride of the South Color Guard throughout her college career. Growing up, she was "self-conscious" and would cover up with jackets "even when it was super-hot outside" (Ivy). She faced people's laughter, fear, stares and apprehension toward her all her life, but now she knows she is "beautiful and that God made me and God makes no mistakes" (Ivy). Winnie Harlow inspired Ivy, providing her "confidence and self-esteem" to "post more

on social media” of her true skin, and she knows others with vitiligo have been inspired too (Ivy). She is appreciative of models “who are not afraid to show their skin” as well as the “companies” who employ “models with vitiligo” (Ivy).

Mandy Osborne is a secretary at Center Hill High School who was diagnosed with vitiligo in 2015. She first noticed “patches around” her “mouth” and her “eyes” and consulted with her dermatologist after online searching led her to believe she was eating too many lemons (Osborne). Osborne’s vitiligo is induced by the sun, becoming more noticeable during the spring and summer months, and no one in her family has a history of vitiligo. Her parents were tested for “hypo-thyroidism” and that combined with “Hashimotos is an autoimmune disease that is common” in those who have vitiligo (Osborne). Even though makeup is not her “favorite thing to do,” she has come to love “Clinique Even Better and Clinique Matte foundations” because “it works” in covering the patches on her face (Osborne). Devontae Shuler, an Ole Miss basketball player, is her favorite player because “we share this vitiligo connection” (Osbourne).

World Vitiligo Day is in the process of becoming recognized by the United Nations and/or the World Health Organization. As of now the VR Foundation and VITSAF are working to collect signatures for the petition to have World Vitiligo Day recognized on June 25. The first World Vitiligo Day was celebrated in 2011 and continues to grow with each year, gaining a new purpose to not only raise awareness of vitiligo, but “to include recognition of the bullying, social neglect, psychological trauma and disability of millions of people affected by vitiligo” (VR Foundation, b).

Literature Review

Most studies conducted in the examination of vitiligo have focused on the psychological effects of the condition. Kent, Gerry and Al'Abadie, Mohammed conducted a survey with a quantitative and qualitative component with 614 vitiligo patients in the United Kingdom to examine “assess the nature and extent of the social and psychological difficulties” of those with vitiligo. Results from the “12-item version of the General Health Questionnaire (GHQ)” along with an “open-ended question” conclude that there are “social and psychological consequences of the condition” (Kent, Gerry and Al'Abadie, Mohammed). Silvan conducted patient interviews and concluded that they “struggle with issues of shame and low self-esteem” (Silvan). Silvan also commented on several studies that indicated patients who have vitiligo, had undergone the traumatic loss of someone or extensive stress (Silvan). Another study had 37 patients with vitiligo and 37 patients with severe acne complete the “Liebowitz Social Anxiety Scale, the Hospital Anxiety and Depression Scale, and the Dermatology Life Quality Index” to “investigate the social anxiety, quality of life, anxiety and depression” in those with vitiligo and severe acne (Salman, Andac, et al.). It was concluded that “social anxiety, depression, and anxiety levels” were “significantly higher” than those without vitiligo and severe acne (Salman, Andac, et al.). The patients’ quality of life was also “impaired in both patient groups” (Salman, Andac, et al.). Porter, et al., conducted a self-administered questionnaire with 62 patient responders and the answers indicated the patients undergo a “great deal of anxiety and psychological distress because of their vitiligo” (Porter, Judith, et al). Another study in the United Kingdom emailed a survey to “675 members of The Vitiligo Society” and “one hundred and sixty-one members responded” (Teasdale,

Emma, et al.). This survey was “aimed to explore people’s views and experiences of seeking health information and help for vitiligo” (Teasdale, Emma, et al). Results showed that many healthcare professionals and providers seemed to have “dismissed” the concerns of patients, which could have been due to their lack of knowledge on vitiligo (Teasdale, Emma, et al). It was also concluded that the “needs of people with vitiligo” are “poorly met” when it concerns medical information about the condition (Teasdale, Emma, et al). A review analysis of vitiligo patient stories and how it affects their mental health conclude that physicians need to have a better understanding of vitiligo patients and take into consideration their “self-esteem and QoL” (quality of life) (Grimes & Miller, 2018).

Research Objective

Despite the recent much needed awareness brought to the condition of vitiligo by celebrities and psychological and qualitative research conducted thus far, little work has been done to evaluate the portrayal of vitiligo through social media. This may be particularly important given recent shifts in awareness of the condition. Therefore, the objective of this study is to describe how vitiligo is portrayed in social media using demographic characteristics, including race, gender, age, etc. using content analysis procedures.

METHODS

Design

This study is a cross-sectional content analysis on social media of the portrayal of vitiligo according to demographic characteristics.

Selection of Content

This content analysis involved analyzing posts on Instagram with the hashtag “#vitiligo”. Only the pictures were analyzed, not the captions on the posts. Instagram was selected for use because of the requirement of a picture as the minimum requirements for posting relative to other social media platforms such as Facebook and TikTok. At the time of data collection, Instagram housed approximately 659,074 posts under “#vitiligo”. The 100 first posts that met the study’s inclusion and exclusion criteria requirements (Table 1) were pulled by a non-judge investigator on March 27, 2022.

Table 1: Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
<ul style="list-style-type: none">• Must be post a live human	<ul style="list-style-type: none">• Product advertisements• Video posts• Posts used for codebook exams• Posts used for judge training• Duplicate posts• Posts of the same person

Coding strategy

Vitiligo Instagram posts were analyzed with a codebook designed specifically for this study (Appendix 1). The codebook was modeled after the codebook from "Fitspiration" on Social Media: A Content Analysis of Gendered Images (Carrotte et al., 2017). Only Instagram pictures of the posts with "#vitiligo" were analyzed, none of the captions or texts were considered in coding. The codebook was created and housed on a Microsoft Excel workbook that included 25 sheets. The first worksheet in the workbook included the page included in Appendix 1. The remaining worksheets included tabs named by level of each variable and a picture depicting an example of each variable level.

The variables evaluated included 1) number of people in the post (1, 2 or 3 or more), 2) gender (male, female, unable to determine, multiple genders), 3) race (Black, White, Asian, other, undetermined, multiple races), 4) contrast severity of vitiligo spots (mild, moderate, severe, multiple severity contrasts), 5) severity of area that was affected by vitiligo (mild, moderate, severe, multiple severity areas), 6) age (infant, child, teenager, younger adult, middle age, senior, multiple ages), 7) amount of clothing coverage (minimal, moderate, full, multiple coverages), and 8) amount of body included in the post (25% or less, 50% or less, 75% or less, 100% or less, multiple body included). Two independent coders both analyzed 100 pictures selected by a non-judge investigator each using the coding form designed for this study (Appendix 2). The coding form consists of the image number, coder initials and the picture analyzed in the corner of the form. The coders highlighted the selections in the categories that they judged to be appropriate for the picture reviewed.

Prior to coding for the study, both judges were trained in using the codebook and coding before the analysis process using example posts not included in the study. Each judge evaluated five Instagram pictures from #vitiligo that met inclusion and exclusion criteria using the coding form found in Appendix 2.

Data Management

Data was transferred from the final 200 coding forms to Excel using numerical codes to depict each judge's selection of variable level. Data was organized as a column for each judge's selections across eight variables for 16 columns and 100 rows for each Instagram picture examined. Data was then transferred to IBM Statistics version 28 for analysis.

Data Analysis

Interrater reliability was analyzed between the two judges using Cohen's kappa (K) for categorical variables (qualitative items). Cohen's kappa is often considered a more robust measure than simple percent agreement calculations, because its calculation considers the possibility of agreement occurring by chance. Cohen's Kappa ranges from 0-1, indicated strength of agreement among judges. Values of 0.60 and higher are typically considered acceptable values in the literature (McHugh).

Frequency analysis was conducted by tabulating frequencies of the levels of each of the eight practice variables for each judge including 1) number of people, 2) gender, 3) race, 4) severity (contrast) of vitiligo spots, 5) severity (area) that was affected by vitiligo, 6) age, 7) clothing coverage, and 8) amount of body included in the post.

RESULTS

Interrater Reliability

Cohen's Kappa (K) for categorical variables was used to calculate interrater reliability for each of the eight variables used in this study (Table 2). Values ranged from a low of 0.37 for age to a high of 0.87 for gender.

Table 2: Interrater Reliability of Judges

#	Variable Name	Kappa	Description	Variable Levels
1	Number of persons	0.72	Number of patients illustrated	One Two Three or more
2	Gender	0.87	Gender of vitiligo patients represented	Male(s) only Female(s) only Unable to Determine Multiple Genders
3	Race	0.50	Patient's race	Black(s) only White(s) only Asian(s) only Other(s) only Undetermined Multiple Races
4	Severity - Contrast	0.47	Strength of contrast of vitiligo	Mild only Moderate only Severe only Multiple severity contrasts
5	Severity - Area	0.43	How much skin is affected by vitiligo	Mild only Moderate only Severe only Multiple severity areas
6	Age	0.37	Age of vitiligo patients	Infant only Child only Teenager only Younger adult only Middle age only Senior only Multiple ages
7	Clothing Coverage	0.60	Amount of clothing present	Minimal only Moderate only Full only Multiple coverages
8	Amount of Body Included	0.74	Amount of the body in photo	25% or less only 50% or less only 75% or less only 100% or less only Multiple body included

Variable Frequencies

In examining frequencies of each level of all eight variables in the study, it appeared that most Instagram posts on #vitiligo were very generally characterized as including one younger white female wearing moderate amounts of clothing with varying degrees of strength of contrast in their skin pigments, that covers a small area, with varying amounts of the body shown in the post.

Table 3: Variable Frequencies

#	Variable Name	Description	Variable Levels	Judge 1	Judge 2
1	Number of persons	Number of patients illustrated	One	88	93
			Two	10	5
			Three or more	2	2
2	Gender	Gender of vitiligo patients represented	Male(s) only	23	24
			Female(s) only	69	72
			Unable to Determine	3	1
			Multiple Genders	5	3
3	Race	Patient's race	Black(s) only	21	21
			White(s) only	45	42
			Asian(s) only	10	8
			Other(s) only	0	12
			Undetermined	22	17
			Multiple Races	2	0
4	Severity - Contrast	Strength of contrast of vitiligo	Mild only	36	30
			Moderate only	33	45
			Severe only	26	24
			Multiple severity contrasts	5	1
5	Severity - Area	How much skin is affected by vitiligo	Mild only	52	72
			Moderate only	24	16
			Severe only	20	11
			Multiple severity areas	4	1
6	Age	Age of vitiligo patients	Infant only	0	0
			Child only	4	3
			Teenager only	19	3
			Younger adult only	53	81
			Middle age only	23	12
			Senior only	0	0
7	Clothing Coverage	Amount of clothing present	Minimal only	34	29
			Moderate only	58	65
			Full only	7	6
			Multiple coverages	1	0
8	Amount of Body Included	Amount of the body in photo	25% or less only	19	24
			50% or less only	28	26
			75% or less only	18	16
			100% or less only	33	34
			Multiple body included	2	0

DISCUSSION

Interpretation of Results

When examining the interrater reliability of the two judges in this study, a conservative estimate (Cohen's Kappa) was used for evaluation to avoid bias associated with agreement among judges occurring by chance. It is not surprising, however, that more objective variable assessments such as number of people in a post, gender, amount of a body shown in a post, or amount of clothing worn demonstrated more interrater agreement than variables that may be subject to more subjective interpretation such as race, degree of skin pigment contrast, amount of skin with contrasting pigments, and age.

It is apparent from the data collected that there was a meaningful trend toward younger people appearing in Instagram posts. This trend may not be surprising when considering the segment of the population more likely to use Instagram as a source of social media, although middle-aged individuals also appeared often in posts. The fact that most posts included a single person could be indicative of many posts being comprised of selfies. Females with vitiligo appear to be more commonly portrayed on Instagram than males. While published statistics suggest that males and females use Instagram fairly equally, it may be that females tend to post pictures more commonly than males, regardless of vitiligo status. Similarly, the higher frequency of white individuals with vitiligo portrayed only versus black may also be a function of differences posting between the racial groups, versus differences in prevalence of vitiligo in both groups. The distribution of severity of vitiligo among Instagram posts seemed to be fairly consistently distributed in terms of severity of pigment contrast and amount of area with distortion in pigments, as well what percentage of the body is illustrated in posts. Finally, while

moderately clothed individuals were most commonly portrayed, there still remained nearly 30% of posts including individuals with vitiligo that were minimally clothed, presumably for the purpose of illustrating pigment differentiation.

Implications and Future Research

The sample of Instagram posts used in this study appeared to reflect a wide diversity of individuals with various forms of vitiligo across ages, races, and genders. This is encouraging for those making efforts to create awareness and positive perceptions around the condition of vitiligo. However, replication studies are warranted to verify if similar trends exist in other samples of posts, especially given the lower interrater reliability ratings for some of the more subjective variables measured. Studying other social media platforms, or other media in general, may help determine whether this vitiligo sample is really reflective of the overall vitiligo population or more vastly affected by Instagram, itself. Analysis of more than just pictures, but also associated captions and comments might provide deeper understanding of how vitiligo is portrayed. Determining the extent to which vitiligo is portrayed either negatively or positively in social media may further “move the needle” with regard to the success of vitiligo campaigns advocating for positivity around the condition. Such analysis, especially if content analysis, is dramatically more complex than the research conducted for this study. Use of social and behavioral theory (such as objectification theory in social psychology (Carrotte et al., 2017)) may also provide guidance in this future work and should be integrated into future analyses.

Despite the diversity with which vitiligo was portrayed in our sample, the mental health ramifications of the condition cannot be ignored among this diverse population.

This is where pharmacists can play an especially key role in the care for vitiligo patients who may be suffering from compromised mental health. Therefore, while not always apparent, there can be an important role for student pharmacists and practicing pharmacists who work with vitiligo patient and their possible comorbid mental health conditions.

Limitations

There are several limitations associate with this research. Use of a personal instagram account by the non-judge investigator in this study may have introduced bias. It is noted in other similar research that “No best practice tools are available for systematically searching social media, and various websites’ default search algorithms do not allow systematic searching.” With grant funding, use of platforms such as tagboard.com which has the ability to track recent, public posts with hashtags across Instagram, Facebook and Twitter.

Conclusion

To our knowledge, this is the first content analysis of vitiligo on social media, at least among published works. The diversity of demographics and severity of vitiligo in individuals posted on instagram is encouraging for better acceptance of the condition on a societal level for people with varying vitiligo severity among various genders, races, and ages. Future content analysis studies that dig deeper into social media posts for comments, captions, and positive and negative portrayals will help determine whether positive vitiligo campaigns are effective. Pharmacists and student pharmacists should also stay aware of, and vigilant to, any possible comorbid mental illness from which individuals with vitiligo may suffer.

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APPENDIX 1 (CODE BOOK)

#	Variable Name	Description	Variable Levels
1	Number of persons	Number of patients illustrated	One or more
2	Gender	Gender of vitiligo patients represented	Male(s) only Female(s) only Unable to Determine Multiple Genders
3	Race	Patient's race	Black(s) only White(s) only Asian(s) only Other(s) only Undetermined Multiple Races
4	Severity - Contrast	Strength of contrast of vitiligo	mild only moderate only severe only Multiple severity contrasts
5	Severity - Area	How much skin is affected by vitiligo	mild only moderate only severe only Multiple severity areas
6	Age	Age of vitiligo patients	infant only child only teenager only younger adult only middle age only senior only Multiple ages
7	Clothing Coverage	Amount of clothing present	minimal only moderate only full only Multiple coverages
8	Amount of Body Included	Amount of the body in photo	25% or less only 50% or less only 75% or less only 100% or less only Multiple body included

APPENDIX 2 (CODING FORM)

Vitiligo Content Analysis Study Coding Form

Image number:

Coder Initials:

Please highlight selections in yellow

Number of persons: 1 only
2 only
3 or more

Gender: Male only
Female only
Undetermined
Multiple Genders

Race: Black only
White only
Asian only
Other only
Undetermined
Multiple Races

Severity (Contrast): mild only
moderate only
severe only
Multiple severity contrasts

Severity (Area): mild only
moderate only
severe only
Multiple severity areas

Age: infant only
child only
teenager only
younger adult only
middle age only
senior only
Multiple ages

Clothing Coverage: minimal only
moderate only
full only
Multiple coverages

Amount of Body Included: 25% or less only
50% or less only
75% or less only
100% or less only
Multiple body

Paste Image Here

Post does not meet study
criteria because (highlight):

- It is not a photo of a live person(s)
- It is a product advertisement
- It is a duplicate of a codebook example