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The Stigma of Pigmentary Disorders

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Abstract

One of the major barriers to individuals with pigmentary disorders in achieving their life goals is the stigma of their disorder. This paper provides a review of the existing research regarding stigma reduction, focusing on public stigma, and looking at approaches used within the mental health and other stigmatized communities. A main focus of pigmentary disorder advocates is to eliminate this stigma to remove the barrier it has on success and self-efficacy. Approaching this task from a perspective well-informed by previous research is important to both ensure that stigma reduction resources are spent wisely, and that anti-stigma approaches are effective.

Keywords: Vitiligo; Stigma; Pigmentary disorders

The Stigma of Pigmentary Disorders

Pigmentary disorders harm people in two ways: through the direct effects of the symptoms of the disorder and the painful response of the public to manifestations of the illness stigma. Stigma represents the prejudice and discrimination that results from "culturally constructed marks". They are cues that signal prejudice and discrimination against a group. For example, skin color is the mark of ethnicity which leads to racism. Although research has begun to make sense of the impact of stigma on various pigmentary disorders, including areas such as psoriasis and vitiligo a much broader body of work exists describing the stigma of mental illness [1]. Although there is a difference in the stigma of pigmentary disorders compared to mental illness most notably, the cues of pigmentary disorders are patently obvious while those of mental illness are mostly hidden cogency of mental health stigma research offers guidelines for developing an agenda for beating the stigma of pigmentary disorders. In this paper, we use this literature to pose models of stigma's effect and ways to erase these effects based on this literature.

A Structural Model that Explains Stigma

A social-cognitive model illustrates how stereotypes, prejudice and discrimination negatively impact people in stigmatized groups (see Table 1). Stereotypes are attitudes that the majority of the public holds (e.g., "Most people think women who are blond are unintelligent"), prejudice is the emotional reaction that results from agreeing with these public attitudes (e.g., "Yes, women who are blond are less intelligent - and I'm annoyed when talking to them") and discrimination is the behaviour that results from stereotypes and prejudices (e.g., "She's blond, so I will not take her work seriously"). Mixed methods research on the stigma of mental illness identified beliefs that comprise the set of stereotypes specific to this group. They include dangerousness, incompetence, and blame [2-4]. Similar work needs be done for pigmentary disorders; Table 1 proffers stereotype candidates that might include ideas of cleanliness and infection. Research has also identified various forms of discrimination that result from endorsing stereotypes of mental illness. People labelled with mental illness are less likely to be hired for jobs by employers and rented apartments by landlords [5]. Unnecessarily coercive treatment practices are often promoted, [6] as is segregation of mental health institutions from one's community [7]. Research needs to identify discrimination experienced by people with pigmentary disorders.

There are three types of stigma relevant to both mental health and pigmentary disorders: public stigma, self-stigma, and label avoidance. These types of stigma are summarized in the top row of Table 1. Public stigma occurs when members of the general public endorse stereotypes of pigmentary disorders and act in a discriminatory manner towards individuals with these disorders. For example, a prejudiced landlord who believes individuals with pigmentary disorders are dirty may refuse to rent an apartment to someone who has a pigmentary disorder. Self-stigma arises when an individual internalizes the prejudice and discriminates against themselves. The internalization of stigma harms self-esteem, lessens self-efficacy and leads to the "why try" effect [8]. "Why should I seek a girlfriend? Someone like me is dirty and undesirable." Label avoidance refers to the need to evade being assigned a negative label based on where you are going or how you look. In the case of mental illness, people may refuse to seek treatment to avoid being seen at a mental health program and thus being labelled as "crazy." Likewise, someone with a pigmentary disorder might not go to the dermatologist to avoid being labelled as "dirty."

Ways to Erase Stigma

Public stigma serves as the foundation for forming both self-stigma and label avoidance; therefore, to erase stigma, it is reasonable to start with erasing public stigma. There are various approaches used to change public stigma which can be categorized into three processes: protest, education, and contact [9]. Protest is used to highlight the wrongs of various forms of stigma, chastising offenders for their attitudes through an in-your-face "stop thinking that way!" approach. Evidence shows that protest methods can be a useful tool for significantly changing some behaviours [10]. An example can be seen in the 2000 NAMI Stigma Busters protest, which played a significant role in getting the ABC network to cancel their program

"Wonderland." The show illustrated persons with mental illness in a negative light by showing them as dangerous and unpredictable. Systematized protest can be a very useful means for convincing media networks to stop running stigmatizing programs, but, in some cases, may produce an unintended "rebound" effect. Attitudes and prejudices about the group protested remain unchanged or may actually become worse [11].

Educational approaches to stigma change challenge inaccurate stereotypes the public holds by replacing them with factual information. Educational strategies designed to reduce stigma have, in the past, used various media such as public service announcements, books, flyers, movies, and videos in order to dismiss myths and replace them with facts. Evidence from studies of such interventions indicate that education produces short-term improvements in attitudes. Quantity and longevity of a change in the individual's attitudes and behaviour might be limited however [12,13].

Interpersonal contact with members of the stigmatized group is the third method used for reducing stigma. Contact with a person with mental illness produces greater improvements in attitudes than protest, education, and control conditions. Improvements in attitudes seem to be most prominent when the individual is in contact with a person that disconfirms prevailing stereotypes of the group they belong to [14]. For example, if a prejudiced individual comes into contact with someone who has a mental illness, but has recovered from the illness and become successful in life, then their belief that people with mental illness are incapable of doing anything meaningful will be disproven.

	Public Stigma	**Self-Stigma**	**Label Avoidance**
Stereotype (cognitive)	People with pigmentary disorders are unclean	People with pigmentary disorders are unclean	People with pigmentary disorders are unclean
Prejudice (affective)	Landlord feels they may get infected by Bob because he has a pigmentary disorder.	I am a person with a pigmentary disorder and am therefore disgusting. Who would want to date me?	I have a pigmentary disorder and am ashamed to be seen as "dirty"
Discrimination (behavior)	Landlord won't rent apartment to Bob	"Why try" and I stop looking for a relationship	I don't seek out a dermatologist

Table 1: A Matrix for Understanding Stigma.

Implications

We generated some ideas here that might be used to better understand the stigma experienced by people with pigmentary disorders. Future research and advocacy partnerships need to test hypotheses that emerge from this review. Answers that are still needed include the identification of common stereotypes of pigmentary disorders and how people with pigmentary disorders are discriminated against. Through understanding this, we will be able to find effective ways to challenge the stigma of pigmentary disorders. As advocates continue to struggle with the egregious effects of stigma, they need to understand that not all efforts are effective. Thus, it is essential to evaluate programs using methods based on sound theory. This kind of program may lead to greater opportunities for people with pigmentary disorders, replacing stigma with social acceptance and inclusion.

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