

Vitiligo as a psychosocial disease:

apprehensions of patients imprinted by the white

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Do Bú EA, Alexandre MES, Scardua A, Araújo CRF. O vitiligo como uma doença psicossocial: apreensões de pacientes marcados pelo branco. *Interface (Botucatu)*. 2018; 22(65):481-91.

This study aimed to show the comprehension that patients bearing vitiligo have over their condition, also assessing the association with their health and disease concepts. It is a qualitative research with descriptive and exploratory purposes, carried out from an epidemiological survey throughout the years of 2010-2013, with records from a dermatology outpatient care sector of a seminal hospital located in the city of Campina Grande – Paraíba, Brazil. It was identified that from the 832 existing records, 13 were of vitiligo patients and, from them, eight agreed to be part of this study, answering a semi-structured questionnaire. Data examination was made using the Thematic Content Analysis technique, identifying four categories. Results indicated that the process of being stricken with the disease is directly related to social practices that target the “stained” subject, over whom vitiligo has imprinted its patches.

Keywords: Vitiligo. Stigma. Psychosocial disease. Psychodermatology.

O presente estudo teve por objetivo apresentar a compreensão de sujeitos portadores de vitiligo sobre sua afecção, avaliando também a associação com a concepção de saúde-doença. Trata-se de uma pesquisa qualitativa de caráter descritivo e exploratório, realizada a partir de um levantamento epidemiológico do período de 2010-2013, em prontuários do ambulatório de dermatologia de um hospital de referência localizado na cidade de Campina Grande – Paraíba, Brasil. Identificou-se que de 832 prontuários existentes, 13 pacientes possuíam vitiligo e, destes, apenas oito aceitaram participar do estudo, respondendo a um questionário semiestruturado. O tratamento dos dados ocorreu por meio da técnica de análise de conteúdo temática, identificando quatro categorias. Os resultados indicaram que o processo de adoecimento está diretamente ligado às práticas sociais que são direcionadas ao sujeito “manchado”, sobre o qual o vitiligo imprimiu suas marcas.

Palavras-chave: Vitiligo. Estigma. Doença psicossocial. Psicodermatologia.

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Introduction

The skin is one of the main organs for human beings, especially because it is protective and allows interpersonal interactions, being characterized, then, as mediator between one and the world as well as one's peers. Thus, the skin represents the main connecting channel between subject and world, if not the main one, certainly the first one¹⁻⁵.

It is known that a number of diseases attack the skin, e.g. vitiligo, that estimates to strike about 1% to 2% of the population worldwide, affecting both men and women in a similar way, more preferably between the ages of 10 and 30^{6,7}. The disease distinguishes itself for provoking skin depigmentation, creating white patches on the skin that are results of the reduction of melanocytes from the epidermis and/or loss of their function⁶⁻¹².

Vitiligo may surface in localized or generalized ways and its diagnosis occurs by clinical examinations and/or biopsies¹¹. When localized, it is subdivided into focal, expressed in a specific area of the body, with no defined distribution, or segmental, characterized by unilateral markings on the body. Moving onto generalized manifestations, it may be acrofacial (presence of typical lesions on the distal extremities and face), vulgaris (achromic maculae of random distribution) or mixed (acrofacial and vulgaris)¹²⁻¹⁵.

Regarding the vitiligo etiology, there is still no consensus, and among the hypotheses that are used to explain what triggers the disease, we have emotional related factors, which sets it in the group of psychodermatological disorders^{4,16}. It is one of the most intriguing psychodermatological disorders, as it is asymptomatic and, consequently, does not show any adversities that affect the survival of its carriers^{4,9,11,12,16-20}.

Due to the aforementioned, various physicians pay no attention to the graver aspect of the disorder, which consists on the psychological and emotional implications to the patient. Thus, they end up concentrating on therapeutic procedures that focus on medications, or even coming to the point of discouraging the patient from carrying on with the treatment, stating that it 'only' has an aesthetic aspect. Such affirmation is received painfully by the patient, who has their suffering belittled by the one who should take it into consideration, what might directly affect the subject self-esteem²⁰.

Pain becomes even more agonizing due to socially established relationships, in which the individuals who bear a chronic skin disorder, such as vitiligo, are stigmatized and judged in relation to those who have no visible skin surface alteration^{4,11}. Thereby, it is possible to identify stigmatization processes, which by biological and/or social traces are imprinted on the subject negative contrasts concerning the others. When dealing on stigma, Goffman^{21,22} underlines that when we perceive the other as a carrier of 'different' characteristics, we see them as inferior, resulting in social discrimination.

It is observed, therefore, the psychosocial implications on the individuals that have vitiligo, who will deal directly, on the social dynamic, with these attitudes. This becomes aggravating, once "the individual's psychosocial health is dependant (greatly) on the external appearance and on the instinctive acceptance of his/her skin characteristics, by the other components of the social group"¹ (p. 18).

These implications tend to be intensified, above all, because in popular imagination, there is no distinction between the disease's negative attributions and the representation of the subject, expanding them over to their own self^{23,24}. Accordingly, the quality of life of these people may suffer negative variations^{25,26}.

Considering psychological and biological factors as agents in triggering and progressing skin diseases, it is noticeable the development of studies aiming to ponder over the theme from a theoretical-practical referential according to Psychology and Dermatology. Thus, in a bidirectional manner, we have the inception of the branch of knowledge known as Psychodermatology, deriving from the intersection between the knowledge cores of the aforementioned areas. From this perspective, the subject can be comprehended as a whole being, beyond the dualism psyche/body, also taking into account the social aspects of falling ill^{4,27-30}.

When it comes specifically to vitiligo, some treatments guided by the Psychodermatology referential have encountered as a result the regression of the spots or even their stagnation^{23,26,27,29-31}.

Thus, we have a promising area that still in need of further investigation, due to the complexity it is rooted in, surrounding a number of biopsychosocial issues.

Due to the complexity and importance to know the issue through the vitiligo patients' perspective, once the literature presents itself as incipient with investigations that portray the way these people understand, perceive and face the disorder, the current study had the objective to analyse their illness comprehension, as well as to evaluate the association with the health and disease concepts.

Method

This is a qualitative study, with a descriptive and exploratory approach³², carried out from data collection that was obtained with medical records from a dermatology outpatient care sector of the University Hospital, seminal when it comes to assistance of this nature, located in the city of Campina Grande – Paraíba, Brasil.

From an epidemiological survey throughout the years of 2010-2013 of the dermatology outpatient care sector of the hospital mentioned above, aiming to get a hold of patients diagnosed with vitiligo (International Classification of Diseases – IDC – L80), it was identified that from the 832 existing records, 13 had the aforementioned diagnosis. These were contacted according to the data that were available on the records, and then the reason for the approach and the objectives of the study were explained. Among the total number of people contacted, eight patients were willing to participate on the study, all of them residing in the state of Paraíba – Brazil. It is important to highlight that the outpatient care sector is the only one in the municipality of Campina Grande (PB), also serving the surrounding cities, which offers free service for the population that bear this psychodermatologic disorder.

In order to collect the data, it was utilized a list with questions that were related to the sociodemographic profile of the participant (sex, age and skin color) and a semi-structured questionnaire that comprised the following questions: 'For you, what is health?'; 'In your opinion, what is disease?'; 'For you, what is vitiligo?'; 'Do you associate the appearance of vitiligo to some specific factor? If yes, what?'; 'How long have you had vitiligo?'; 'How do you see yourself with vitiligo?'; 'How do you believe you are seen by society?'. Sociodemographic data obtained from these, along with the visibility the spots had and the time they have vitiligo are described on the Table 1.

Table 1. The study participants' characterization

Sex	Age	Skin Color	Level of Education	Patch Visibility	Time bearing vitiligo
Masculine	34	Brown	Lower secondary	Exposed	3 years
Feminine	19	White	Higher degree (in progress)	No exposition	14 years
Feminine	54	Brown	Illiterate	Exposed	12 years
Masculine	14	Brown	Lower secondary	Exposed	3 years
Feminine	34	Brown	Upper secondary	Exposed	4 years
Feminine	42	Brown	Higher degree	Exposed	15 years
Masculine	31	Brown	Upper secondary	Exposed	4 years
Feminine	25	Brown	Upper secondary	Exposed	25 years

Note. The semantic value of the skin color, here translated as brown, in Portuguese is equivalent of the term *Parda*.

Data were collected after the authorization by the Ethics Committee in Research Involving Human Beings (*Comitê de Ética em Pesquisa Envolvendo Seres Humanos*), with report number 451.873 and Certificate of Presentation for Ethical Appreciation (*Certificado de Apresentação para Apreciação Ética*), with due authorization from each participant and/or their respective legal guardians, by signing

the Informed Consent Form (*Termo de Consentimento Livre e Esclarecido* - TCLE), in accordance with Resolution n. 466/12 by the National Health Council (Conselho Nacional de Saúde)³³.

To analyze data connected to the open issues, it was utilized the Thematic Content Analysis technique, as proposed by Bardin³⁴. Thus, the content of the interviews was organized in theme-based categories, defined from a body of expressions that share common meaning.

Results

The theme-based categories will be shown from a general definition, followed by examples of contents, which characterize them, targeting the reader's best comprehension. In accordance with that, four theme-based categories were established that permeate the concepts of health-disease, vitiligo, triggering and progressional factors, as well as matters associated to psychosocial implications to the carriers.

Health-disease conception

The concept of health was presented by the participants in contrast to the definition of disease, in order to allude to the subject's well-being. Accordingly, being healthy brings on the aptitude to work, to play sports and to enjoy leisure time, whilst the disorder characteristically would hinder the realization of any of these tasks.

"Health is a state of well-being. When you are not sick...you are in good health". (participant 2)

"[...] health is just like this, you being healthy". (participant 4)

"disease is when a person is never healthy, only being sick all the time". (participant 6)

"Health is being able to feel good with yourself... to be able to play a sport, go out, enjoy leisure time, have a good time with the family". (participant 8)

Vitiligo definition

Vitiligo was defined by the participants from two distinct dimensions, in which one of these is related to biological matters whereas the other one points towards a comprehension of the disease permeated by unflattering remarks. When it comes to the biological aspects, vitiligo is referred to as an autoimmune, non-communicable disorder, which has no side effects, although it may leave a 'defective' body. Conversely, vitiligo has been labeled as being appalling, implicating a level of discomfort for the carrier, also being referred to as some type of emotional disorder, topic that will be best covered on the next section. It is imperative to highlight that understanding such distresses could be accomplished by information given during doctor's appointments and internet searches done individually, aside from the personal contact.

"It is an autoimmune disorder". (participant 1)

"it may leave a defective body". (participant 2)

"it is a skin abnormality". (participant 3)

"It is appalling!". (participant 5)

"I think it is an emotional disorder". (participant 6)

"When I went to the doctor, she explained about these little white patches". (participant 7)

"what I know about vitiligo is what I have looked up on the Internet". (participant 8)

Vitiligo triggering and progression

Vitiligo triggering and progression were associated to factors of an emotional nature, especially to stress and anxiety. Thus, stress is ascribed to events connected to working conditions and family matters, whereas anxiety is shown as a characteristic inherent to the subject.

"I guess it was stress after all". (participant 2)

"there were days I got so worked up because of the people working with me and I am really anxious as well". (participant 3)

"I quit my job around 3 years ago, right, and then I got into a lot of debt and I still had to provide at home [...] Even the doctor said that it could all have happened due to stress". (participant 4)

"family stress, from fights with my father". (participant 5)

"I have always been extremely nervous as well, if I have anything to straighten out, it has to be then and there, you know?". (participant 6)

"it spreads when we are stressed, anxious". (participant 7)

"[...] much stress when I was a child" (participant 7); "I get really stressed, very worked up". (participant 8)

Vitiligo visibility (stigmatization and discrimination)

This section refers to a psychosocial dimension directly related to interpersonal relations the participants of this research have gone through. Thus, visibility of the spots, as well as size and location, were referred by the participants as causes for distress, not only when it comes to aesthetical and social matters, but, above all for the discrimination and stigmatizing looks received in several social situations. Stigmatization and discrimination were "justified" by the participants themselves as a sign of fear of contracting the disease. In face of this affliction, a number of resources are utilized in order to conceal the signs of vitiligo, for instance, the use of make-up.

"When I was little I suffered a lot from discrimination, because the spots were big". (participant 1)

"if someone is sitting next to me, then they begin to cower, to get away in fear, they are afraid to catch something". (participant 3)

"parents giving me the stink eye... they think they can catch it". (participant 4)

"as I am always wearing make-up, people never notice it and so I do not feel embarrassed". (participant 5)

"I have these little patches on my hands, but, as they have not grown, I do not really mind". (participant 6)

"I have always worn make-up as well". (participant 6)

"I wear foundation with sunscreen". (participant 7)

"because I am either wearing some make-up or some foundation to conceal it". (participant 8)

Discussion

From the results, it is possible to notice that in a perspective, the health-disease concept, especially when it comes to the negative connotation, sets up a relation with the vitiligo definition as, while a negative experience, it seems to approach the definition of the disease. On the other hand, vitiligo cannot hinder the realization of daily activities, at least from a functional standpoint, which, in its turn, puts it further apart from the semantic value attributed to the disorder by the participants. However, it is valid to highlight that vitiligo starts to be referred to as a nuisance and a hindrance for the development of certain activities, due to the types of interpersonal relations that are established, which are distinguished by the looks of prejudice and stigma of the others around. Hence, it is possible to suggest that, more than a disorder of a strictly biological nature, vitiligo aggregates psychological and social aspects, being a psychosocial disorder.

Accordingly, it is the other who brings forth the state of someone with a 'stained' skin and passes judgement, also circumscribing the carrier of vitiligo as a threat. The menacing sense is founded in the belief that we are dealing with a communicable disease, justifying the need for certain distance, aggravating the differences among groups, in a way to widen their frontiers. This situation is assimilated by the participants as a cause for stress, to either those ones who have patches that are more exposed, who directly deal with prejudice, or those ones that have patches that are more discreetly located, not being easily noticed, needing different strategies to conceal the spots from the looks of the society nonetheless. More specifically, we can accentuate the use of make-up by the participants, as an active strategy in the process of avoiding prejudice.

Similar results were obtained by Kent³⁵, corroborating the correlation among patch exposition, stigma perception, and low self-esteem of the vitiligo bearer. Ongenae and collaborators³⁶ identified a grieving factor that increases the visibility of the spots, besides size and location, there is also skin color. Thus, individuals who have darker skins, on which the white patches have greater contrast, showed an increased index of low self-esteem and difficulty to establish social connections.

Stigma, prejudice and discrimination towards people who have vitiligo was also observed by Kent³⁵, Lopes²⁷, Müller²⁹, Müller and Ramos³⁰, Menezes et al.³¹, Oliveira et al.²⁶, Sant'Anna et al.²³, Pahwa et al.³⁷, who highlighted the negative implications these actions had on their self-esteem and quality of life, besides the difficulties to establish interpersonal relations and consequently to fit in the social dynamics. Hence, we have a process of differentiation between groups, in which the disrespect to the singularity of those imprinted by the white culminates in their social exclusion.

It occurs, according to Jodelet³⁸, because members of a certain group tend to praise their own characteristics, depreciating the others', scorning them, in a way to demonstrate superiority and shield themselves against those who are labelled as different. Such phenomena came to be intertwined with social and cultural construction and are easily identified in the history of diseases throughout time.

When it comes to demonstrating the individual search for knowledge on Vitiligo, as well as doubts and associating its causes to cancer and/or poor performance of certain organs in the body, they tend to point to the lack of information obtained from the outpatient care sector. This was also observed by Nogueira and collaborators²⁰, as a phenomenon that seems to occur with certain frequency in Brazil, showing, among other aspects, that patients are guided to face vitiligo as if it were something really minor, suppressing and/or keeping the complaints and psychosocial suffering to a minimum. Internationally, following literature review by Ongenae et al.³⁶, this type of behavior was also observed.

Such scenery reveals the importance of communicating about the diagnosis in a way to offer a meaningful amount of information covering the disorder, welcoming the patient's doubts and

consequently granting means for the subject to forge his/her own knowledge on the disease. This kind of demeanor would minimize the occurrence of iatrogenesis, such as angst and depressive symptoms, when the patient is faced with the 'unknown', which imprints his body with invasive marks; the absence of this behavior withholds the right to interrupt the disorder progress from the patient^{26,27,36,37,39}. It is important to ponder over other psychosocial impacts that being diagnosed with vitiligo provoke on the patient's life, such as sadness, dread, anxiety, insecurity, low self-esteem, shame, discrimination, stigmatization, among others^{18,19,25,27,37}.

Consequently, not only is vitiligo being constantly presented as a result of adverse emotional states, such as anxiety and stress, as mentioned in the literature^{4,7,18,19,25,27,35-37} and observed in this study, but living with the disease also piles up as another stressing element for the carriers, once there is no prediction as to where a spot will appear, aggravating anxiety and stress. Thus, this situation may contribute to continuing the progression of vitiligo, making it even harder the stabilization and/or regression of the patches.

Adverse situations that happen in the life of the individuals were also cited as promoters of stress and anxiety, which, consequently, trigger or add to vitiligo progression. So, the participants particularly mentioned losing jobs or work-related problems.

It is relevant to consider the singular manner each individual deals with the disorder, also understanding that some will have more difficulties to adapt than others. Bearing in mind that the prognosis of vitiligo is uncertain, it is observed the earnestness that the patient has to develop new strategies to address and remodel the disorder through mechanisms that are resilient and sensible like the aforementioned make-up. Following this concept, from the experiences of the patients in this study whom associated the triggering of vitiligo to factors of emotional nature, corroborating the pertinent literature, psychological support comes off as significant way to uphold patients who were diagnosed with the affection. This constitutes an environment to welcome the emotional experience when battling the disease, promoting ego strengthening and stimulation of the resilience^{23,26-31}.

These effects were described in the literature referring to vitiligo and other psychodermatological disorders as a result of psychodermatology support^{18,23,26-31}. In a special way, it is highlighted the work of Correia and Borloti¹⁸, carried out with 61 vitiligo bearers, in which it was apprehended the importance of psychological counselling, as support to the best treatment effects, done so with the verbalization of the patients' experiences.

It also must be accentuated a research accomplished by Müller³ associated with 13 vitiligo carriers, that aimed to identify if different ways to treat the disease that were offered (dermatologic; psychodermatologic) would bring results that would diverge when comparing regression and/or stabilization of the patches. It was discovered with clinical examinations that patients that were put through the latter treatment showed a superior degree of regression on the depigmentation, when compared to those who only had the former treatment, also broadening the awareness over their inner conflicts.

Not only so, the aforementioned results also demonstrate that having vitiligo is compared to 'cheating', as the disease makes visible what is more intimate for them, "exposing to anyone the agony of the soul"³ (p. 127), once the affection triggering was associated to factors such as anxiety, angst and stress, arising from losses and/or after traumatic events. Psychosocial conflicts like these showed by Müller³ were identified in this work, which confirm the idea of vitiligo as a psychodermatological disorder and not only as a disease of dermatological nature.

It is important to highlight that besides the pain provoked by the depreciative looks, under an aesthetic dimension, there is also the pain caused by inner conflicts that make an even better connection to the vitiligo causes (adverse situations such as the loss of loved ones or jobs) than the social effect of having such disease. In this sense, what vitiligo brings to the subject is cause for great ache, such as the incapability to handle certain traumatic events, turning the individual susceptible to the depreciative action of the society.

It is also worth mentioning that the work developed by Menezes et al.³¹ concerning a patient bearer of vitiligo and alopecia areata universalis, with whom, besides medical supervision, it was adopted a systematic psychotherapeutic support over the course of five years, assisting the

strengthening of the self-esteem and remission of symptoms such as anxiety. Hence, from the psychotherapeutic support, the patient in question managed to reassign a different meaning to the experience of being a carrier of these psychodermatological disorders, demonstrating new skills to handle the looks, which, in times, are discriminating and stigmatizing from the others, positively adapting to live with such affections.

It is underlined as well the case study²³ carried out with a 43-year-old lady who bore vitiligo for 16 years, in which the appearance of the psychodermatologic disorder was related to a slew of stressing emotional experiences, such as the passing of her brother and the suppression of her feelings. The psychotherapeutic intervention occurred by utilizing a sand game, in which the patient is invited to build characters and stories with the manipulation of the sand, given the chance in this process to externalize intrapsychic conflicts, as the psychologist gathers information and guides the intervention focus.

This way, throughout nine interventional sessions, the referred patient was able to express, recognize and elaborate her psychic conflicts upon a concrete and safe dimension through the game. Notwithstanding the short duration of the process, it was possible to observe the mobilization of psychological resources that resonated in the dynamic of her interpersonal relationships, which suggestively would subsequently contribute to vitiligo stabilization.

Final considerations

Although this work has been carried out with a limited number of participants, from a statistical standpoint, the data that was analysed illustrate that the process where the patient becomes ill is directly linked to attitudes and social practices that are directed to the 'stained' subject, over whom vitiligo has imprinted its patches. For these participants, being stricken with such affection comes off as more than a simple dermatological condition, it is to bear a psychosocial illness that is true, due to looks coming through the eyes of the others, as well as the effects upon their own selves.

Thus, it is of utmost importance to expand in new studies, dealing with even greater samples and focusing on seizing this psychosocial phenomenon, either from the vitiligo bearer's standpoint or from the other social groups'. The concept of health-disease of the participants was intrinsically connected to having the illness; both being categorized as negative experiences.

Hence, even if not crossing boundaries when facing the realization of daily activities, being stricken with vitiligo imposes barriers when it comes to interpersonal relations, resulting in processes that are both stigmatizing and excluding. For the interviewees, this ends up being another stressing factor, which may aid the progression of the existing spots, as well as the inception of new ones. This is a topic that deserves a reflexive exercise, more systematized, in order to identify how this apparent cause-effect connection occurs.

Vitiligo, for being asymptomatic, is still considered by part of the medical community as something that brings no downside to the patients, disregarding several emotional factors that are intertwined with the process of falling ill, as told by the participants here. Thus, we reiterate the importance of Psychodermatology as a field of knowledge and professional practice to better exploration, aiming a therapeutic approach that takes into account the biological, psychological and social aspects for the patient with vitiligo, acknowledging them as whole individuals.

Collaborators

It is stated that Emerson Araújo Do Bú and Maria Edna Silva de Alexandre participated actively in data collection, development of the results discussion and revision of the manuscript. Anderson Scardua participated vehemently in the discussion of the results, as well as in the revision and approval of the final version of this article. Cristina Ruan Ferreira de Araújo actively participated in the review and approval of the final version of this manuscript.

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El objetivo de este estudio fue presentar la comprensión de sujetos portadores de vitíligo sobre su afección, evaluando también la asociación con el concepto de salud-enfermedad. Se trata de una investigación cualitativa de carácter descriptivo y exploratorio, realizada a partir de un levantamiento epidemiológico del período de 2010-2013, en fichas del ambulatorio de dermatología de un hospital de referencia localizado en la ciudad de Campina Grande – estado de Paraíba, Brasil. Se identificó que, de las 832 fichas existentes, 13 pacientes sufrían de vitíligo y de ellos solamente ocho aceptaron participar en el estudio, respondiendo un cuestionario semi-estructurado. El tratamiento de los datos se realizó por medio de la técnica de análisis de contenido temático, identificando cuatro categorías. Los resultados indicaron que el proceso de enfermedad está directamente vinculado a las prácticas sociales que se dirigen al sujeto “manchado”, sobre el cual el vitíligo imprimió sus marcas.

Palabras clave: Vitíligo. Estigma. Enfermedad psicosocial. Psicodermatología.

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