

Moderating Effect of Symptoms of Disease on the Relationship between Alienation and Social Well-being – Case of Vitiligo Patients

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ABSTRACT

Two hundred Vitiligo patients served as participants in the study. Moderation analysis was used to determine the referent effect of symptoms of disease (stress, tension and uncertainty) on the relationship of alienation and social well-being. Symptoms of disease held by patients were found to have significant moderating effect on the relationship between alienation and social well-being. Interaction plot showed aggravating effect of alienation on social well-being. Case study of a subject showed similar pattern about the relationship. Effectiveness of moderator variable in determining the correlation was discussed. Psychotherapist, counselors and researching/practicing medicos need to consider the role of symptoms of disease in diagnosis and for holistic social well-being of Vitiligo patients. Implications and suggestion for future research are proposed.

Keywords: Vitiligo, Alienation, Social Well-being, Leucoderma

Introduction

Since the suffering of vitiligo, alienation becomes a constant companion of patients. That is, personal, emotional and social alienation is the response of vitiligo patients. The vitiligo enables patients to intensify their efforts so that they can survive and evolve. Vitiligo triggers inferiority complex and alienation. Vitiligo patients had a number of challenges that affects social well-being. Often, due to feeling of alienation, the suffering also affects social well-being.

Alienation

Alienation is a form of existential suffering and the subjective experience of being separated from the world resulting from inability to establish meaningful relationships with the world or lack of desire to do so. As a psychological and theological notion, alienation has its origin in both classical philosophy and Christian theology. As a more specifically philosophical term, the concept became prominent in the nineteenth century beginning with G. W. F. Hegel and Karl Marx. In the twentieth century, the notion was further explored, particularly in the schools of phenomenology and existentialism, which included thinkers such as Martin Heidegger and Jean-Paul Sartre. In terms of existential analysis, an alienated person is unable to perceive the questions that life asks him/her, because these questions are asked in the language of values that do not have a personal meaning for him/her: the dialogues with the inner world is ruptured and the dialogue with the outside world is impoverished. Fromm (1955) discussed alienation as the mode of experience in which a person experiences him/herself as an alien or in other words becomes estranged from the self. Horowitz (1966) suggests that alienation implies an intense separation first from objects of the world, second from people, and third from ideas about the world held by other people.

In general, the term 'alienation' refers to a condition or state where an individual or a group of people experience a feeling of being 'rootless' not knowing, meaningless, bondless and no belongingness. Davids (1955) defines alienation as a syndrome composed of five interrelated dispositions: egocentricity, distrust, pessimism, anxiety and resentment. While Charlton (2007) defines alienation as the feeling that life is meaningless, that we do not belong to the world. The most significant contribution to the empirical research is that of Melvin Seeman's interpretation of alienation. Alienation is determined by the discrepancy between what a person expects and what he receives, so the more the expectations are disappointed, the more alienation one feels (Seeman, 1959). Kim (1987) reported a positive correlation between the level of alienation and physical aging in old people and further indicated that old people who feel social, psychological alienation can accelerate physical aging. However, it was explored in an Indian study (Balachandran, Rakhee, & Raj, 2007) that there are gender differences with respect to the feeling of alienation, where elderly men experience less alienation than elderly women. Quite interestingly a study by Durant and Christain (1990) determined that there were higher levels of alienation among old people with selected socio-economic variables like lower health rating, lower education and income.

Social Well-Being

Social well-being is a sense of involvement with other people and with our communities. Many researchers believe that well-being is not just about being happy or content, but also about being actively engaged with life and with other people. Social well-being is the appraisal of one's circumstances and functioning in society. Among the potential benefits of public life are social integration and cohesion, a sense of belonging and interdependence, and a sense of shared consciousness and collective fate (Durkheim, 1951). These benefits appear to provide a foundation for a global definition of a social dimension of well-being (Keyes, 1998). Keyes (1998) operationalized and validated social well-being as consisting of five dimensions: social integration, social acceptance, social coherence, social contribution, and social actualization. People do not begin or maintain the quest for social well-being with the same assets. Social structure facilitates individuals' ability and opportunity to respond successfully to the social challenges of life. Educational attainment and processes of aging generally affect instrumental resources and self-conceptions.

Indirectly, through monetary abnormality, education determines the quality of one's housing and neighbourhood (Karabel & Halsey 1977; Kohn 1969; Kohn & Schooler, 1982; Sewell & Hauser, 1975). Lower socioeconomic status has been linked consistently to diminished physical and mental health. The relationship of age to social well-being is equivocal. Aging and age differences include numerous aspects that are not always consistent. Despite the decline in physical health with age, research illustrates how adults seem to age successfully through several mechanisms. While some self-conceptions (such as personal control) apparently decline with age (Mirowsky, 1995), other studies find that adults, as they become older, feel happier and more satisfied with their lives and report higher levels of some dimensions of psychological well-being (Heidrich & Ryff, 1996; Ryff & Keyes, 1995). The findings suggest that some facets of social well-being, like psychological well-being, may increase with age.

Interpersonal alienation is similar to social isolation, loneliness and interpersonal trust (Ifegawazi, Chukwuorji, & Zachaeus, 2014). Interpersonal relationships have great importance during adolescence, especially for psychological well-being. The sense of well-being during adolescence can depend on the integration and acceptance of the peer group (Corsano, Majorano, & Champretavy, 2006). Alienation among adolescents is predictive of deviant behavior, such as drug use, truancy, crime and suicide and of health-related outcomes, such as symptom load, drunkenness, alcohol use, less exercising and eating unhealthy food on a daily basis (Rayce, 2012). Alienation is an experience which has become more and more a fact of life in these days of modernization. Probably adolescents feel this much more than the older people or children (Kaur, 2015).

Vitiligo

Leucoderma (Vitiligo) is a chronic skin condition that is characterized by patchy loss of skin pigmentation, resulting in irregular white patches of skin. The white patches often change shape, shrink and grow. They may even remain constant throughout the life. They may at times occur symmetrically on both sides of the body. Other than the cosmetic skin problem, many patients face psychological stress, which in turn may result in increased susceptibility to Vitiligo. In India, about 2-5% of the population is affected by Vitiligo. There is a social stigma attached to this disease affecting the social well-being of the patient, especially in countries like India, where the people are dark-skinned. Vitiligo affects 1-4% of the world population (Porter, Beuf, Nordlund, & Lerner, 1979) with no significant difference in its occurrence as regards to the race, age or gender of the individual. Males and females are thought to be equally affected. AlGhamdi, Moussa, Mandil et al. (2012) revealed a wide range of common public misconceptions about vitiligo. More than 20% thought that it was caused by an infection and more than 22% thought that it was caused by a lack of personal hygiene. Other misconceptions included evil-eye, witchcraft (sorcery), and jinn (evil spirits), which all reveal the prevalence of cultural symptoms of diseases related to this disease. Attitudes toward vitiligo patients were also described, with 56.1% absolutely unwilling to marry a vitiligo patient.

Duman, Durmuscan, and Ulkumen (2016) reported that the most common belief regarding the cause of the disease was stress (84%), followed by excessive sun exposure (37%) and heredity (22%). The patients were not hopeless about the cure and control of vitiligo. Indeed, 47% believed their illness would improve with time. 12% reported feeling depressed when thinking about their illness. More than half of the patients knew the name of their illness.

In general, three major types of symptoms viz. stress, tension and uncertainty were reported by the patients and in general researcher also observed through their behavioral pattern. Symptoms of disease observed or verified through number of pathological investigations played a crucial role in treating the patient. Since the

symptoms of disease are behavioural in nature so there is likelihood that they may have overwhelming effects on alienation and social well-being.

Objectives: The objectives of the present study are:

- (1) to examine the moderating effect of symptoms of disease on the relationship between alienation and social well-being.
- (2) to confirm the structure and dimensionality of items of social wellbeing scale by the Confirmatory Factor Analysis (CFA)

Method

Participants

Two hundred Vitiligo patients served as participants in the study. The sample included patients from diverse basic demographic characteristics, namely; age, gender, profession, residential status, family history, etc. In all 32 characteristics of the patient were recorded in order to assess and to prepare detailed case study of selected patients.

The youngest patient in this study was a 13 years girl and oldest patient was 65 year old male. In 77 (38.5%) patients disease started before the age of 20. The duration of disease varied from 1 year to 38 years as the patients having disease for less than one year was excluded from the study. Out of 200 patients 91 (45.5%) were males and 109 (54.5%) were females. Thirty seven (18.5%) patients gave the family history of vitiligo. Fourteen female patients out of 41(37.6%) patients were married. Forty two (46.2%) male and thirty (27.5%) female patients were exposed to vitiligo after marriage. In 106 (53%) cases, the disease was progressive and 94 (47%) non-progressive in nature. In case of progressive type of vitiligo, 65 (32.5%) and 41 (20.5%) patients it was slow and rapid respectively. Vitiligo was extensive in case of 121 (60.5%) patients and 79 (39.5%) less extensive of less than 1cm² in size. Out of 188 cases (94%), 12 (6%) patients were having multiple and single patches respectively. Out of 127 (63.5%), 73 (36.5%) patients reported that they have small and big patches respectively. Majority of patients were found to have patches on their faces. While examining the color of the affected area, it was observed that 151 (75.5%) patients were having milky-white colored patches followed by 38 (19%), 9 (4.5%) and 2 (1%) having white, reddish and pink colored patches respectively. Eighty three patients (41.5%) were observed to have patches in exposed part of the body followed by 77 (38.5%) and 117 (58.5%) on unexposed part of the body. While examining the affected part of vitiligo, female patients were having patches on unexposed part of the body.

Measures

Alienation Scale (AS) was developed and standardized by the researcher (Khan & Husain, 2018) to study the feeling of alienation among Vitiligo patients. It is a bilingual (Hindi & English) scale. The scale comprised of 21 items with 5-point Likert type responses with values anchored as 'Strongly Disagree', 'Disagree', 'Neutral', 'Agree', 'Strongly Agree'. The total score of the scale varies from 21 to 105 and can be inferred as higher the score higher the alienation and vice-versa.

The Content Validity Index (CVI) of Alienation Scale was determined and was in acceptable range. The internal consistency reliability was determined by using Cronbach's alpha. It was found 0.96 which was significant at 0.001 level. Inter reliability of respective dimensions varied from 0.68 to 0.88. The composite reliabilities for factors varied from 0.76 to 0.97. The internal consistency of the scale is excellent and this gives a support that the scale is reliable. (George & Mallery, 2003). The AS is highly reliable and valid.

The **Social Well-Being Scale** (Keyes, 1998) contains 33 items, five subscales with 5-point Likert type responses with values anchored as, 'Very Untrue'(1), 'Untrue'(2), 'Neither true nor untrue'(3), 'True'(4), 'Very True'(5). It was made bilingual (English and Hindi) and was used for data collection. Items were designed to measure five dimensions such as social integration, social acceptance, social contribution, social actualization, and social coherence. The reliability as reported by (Keyes, 1998) using Cronbach's alpha was 0.84. Inter reliability of respective dimensions varied from 0.54 to 0.62.

Cronbach's alpha for the present sample was found 0.97. Inter reliability of dimensions social integration, social coherence, social contribution, social actualization and social acceptance were 0.91, 0.71, 0.86, 0.93 and 0.91 respectively. The internal consistency of the scale is excellent and this gives a support that the scale is reliable (George & Mallery, 2003).

The Confirmatory Factor Analysis (CFA) was carried out to confirm the structure and dimensionality of items. All items significantly confirmed their dimensionality and correlated with their respective unobserved construct. Results showed $\chi^2=971.773$ ($p<0.001$) high Chi-square value, but many researcher have given low importance to it for goodness of fit model. Standardized regression weights were greater

than 0.60 which is very good. Covariances and variances are significant ($p < 0.001$) and is good. Inter-correlations among factors of self-consciousness were very high and ranged from 0.67 to 0.98 ($p < 0.001$). The direct effects of items in their respective factors were very high and confirmed excellent characteristics. Other model fit summary was: RMR=0.06, GFI=0.95, AGFI=0.72, CFI=0.90, RMSEA=0.071 and all parameters are in acceptable range.

Procedure

The Vitiligo (Leucoderma) patients were undergoing treatment at Regional Research Institute of Unani Medicine, Aligarh (Ministry of Health & Welfare, Govt. of India). Data were collected individually from the patients. Consent form was filled up by the patient and researcher shared the goal of the study. Alienation Scale and Social Wellbeing Scale were administered to the subjects after establishing rapport with the participants. Participants generally took 30 minutes time in completing the scales and providing the other relevant informations.

Results and Discussion

Hierarchical (moderator) multiple regression analysis was done to examine the moderation effects on the relationship of predictor and outcome variable. So, we have three variables; a predictor variable (interval scale), an outcome variable (interval scale) and a hypothesized moderator variable (nominal scale), and our goal is to test the interaction between the predictor and the proposed moderator.

Moderation schema for symptoms of disease as moderator of relationship between alienation and social well-being was prepared and showed in Figure 1.

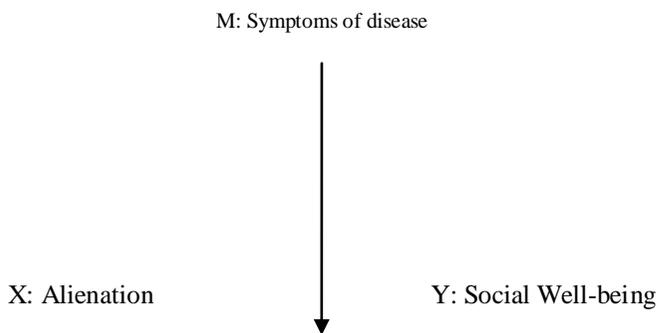


Fig 1: Schema for Symptoms of disease as Moderator between Alienation and Social Well-Being

Table 1.

Hierarchical regression analysis model summary for moderation effect of symptoms of disease on the relationship between Alienation and Social Well-Being.

Model	R	R ²	Change Statistics				
			R ² Change	F Change	df1	df2	Sig. F Change
1	0.856	0.733	-	543.721	1	198	0.000
2	0.862	0.743	0.010	7.894	1	197	0.005

Model 1: Predictors: Symptoms of disease and Alienation

Model 2: Predictors: Symptoms of disease and Alienation, Interaction between Symptoms of disease and Alienation

As shown in Table 1, Model 1 considering symptoms of disease and alienation as predictors without the interaction accounted for a significant amount of variance in social well-being, $R^2 = 0.733$, $F(1, 198) = 543.721$, $p < 0.001$. It can be inferred that symptoms of disease and alienation are the significant predictors of social well-being. Next, the interaction between symptoms of disease and alienation was added to the regression model (Model 2) which again accounted for a significant amount of variance in social well-being, $\Delta R^2 = 0.010$, $\Delta F(1, 197) = 7.894$, $p = 0.005$. On the basis of this analysis it can be inferred that there is a significant moderating effect of symptoms of disease on the relationship between alienation and social well-

being. Further, for visualizing the conditional effect of alienation (X) on social well-being (Y) interaction plot prepared and shown as figure 2.

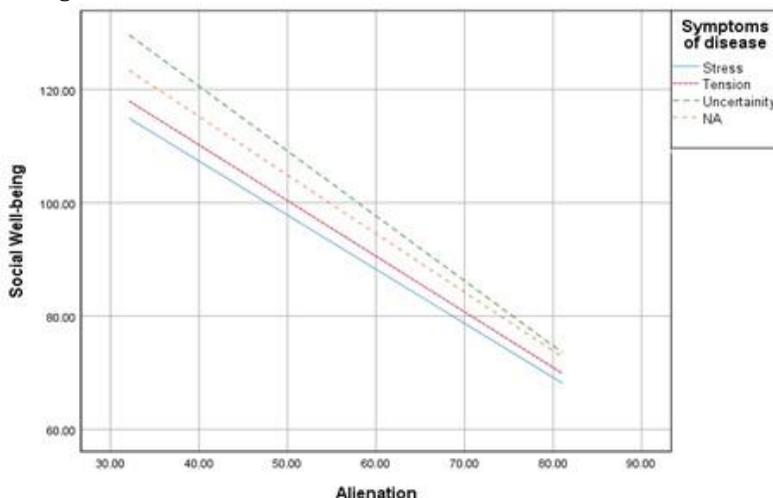


Fig 2: Interaction plot of Symptoms of disease for alienation (X) on social well-being (Y)

Examination of the interaction plot showed an aggravating effect, considering the symptoms of disease of patients, when alienation in increasing social well-being is decreasing. It was also seen that in case of patients down with certain symptoms of disease reported as stress and tension their alienation was high comparing to no symptoms of disease and so as the resulting low social well-being. To support these findings case study of some of the patients was carried out and it was observed that patients having stress and tension were more sensitive towards their appearance and were stigmatized sometimes. Finding based on one of the patient is produced in the following paragraph.

Case Study

The case reported here has Id No. 53 in this study and here narration described as: I am 13-year-old female patient. I was about 6 years old when I was diagnosed as that I had Vitiligo. At first, I did not know what it was but I quickly learned. When I was growing up, I did not care what I looked like. Then, I switched schools and I did not know what kids at school would say or think of me. When I m not at school, I will have my moments when I start to cry and tell myself horrible things like “I am ugly,” “what did I do to deserve this,” and “I’m a horrible person.” I know my family loves me, but sometimes i do not. Now that I am entering my teen years, I have started to care more about myself appearance and self-esteem. I do not look pretty with my spots. Sometimes I wish I could go back to my younger self [who] did not care. I look at pictures of myself without spots and say to myself, “Wow, I did not remember what certain parts of my body looked like and now they look very different.” I am highly stressed many times. I know my teen years will be very different and I will need to turn to my family and friends for support.

On the basis of psychological variables under study, the description of above case is presented in table 2.

Table 2

Alienation and Social Well-being

Variable	Range of scores	Raw Score	Z-score	Interpretation						
				EH	H	AA	A	BA	L	EL
Alienation	26-98	81	1.20		●					
Social Well-being	45-144	52	-1.63							●

EH: Extremely High, H: High, AA: Above Average, A: Average, BA: Below Average, L: Low, EL: Extremely Low

Remark: She feel alienated herself from others (high alienation score) which had adverse effects on social well-being (extremely low score).

Conclusions and Suggestions

The results of the present study confirmed that symptoms of disease are the moderator of relationship between alienation and social well-being. Findings can be supported by an earlier study (AlGhamdi, Moussa,

Mandil et al., 2012). The social stigma attached with the disease, mostly in South Asia, is largely due to white patches prominently standing out on darker skin complexions. The need to belong is one of the strongest human needs and thwarting the need to belong and find meaning can have devastating consequences for wellbeing. Alienated persons may perceive meaninglessness if they do not find fulfillments in social encounters or when there is a lack of group ties and social roles that reflect such ties.

Patients know that coping with vitiligo is definitely challenging; if they perceive that the illness has some meaning in their life then they can make their life more meaningful. Educating the public about vitiligo could lead to recover from symptoms of disease, increased self-confidence, better social integration, and psychological well-being for vitiligo patients. The people should be given health education by medical staff and symptoms of disease can be diminished. The community health workers should provide health education to people. Separate skin clinic should be opened at the centres and skin specialists should be there at the clinics. Understanding how belief symptoms of diseases and misconceptions about skin-related diseases in the community and among individuals are important for the development of programs and policies. Educational programs are needed to develop awareness among common people about common symptoms of vitiligo and the myth associated with this disease.

Implications

The findings of the present study have significant implications in the fields of positive and health psychology, and in the improvement of social well-being of patients.

1. Maintaining distance from work, family, and friends is a common symptom of alienation. When it is so, the person is lacking to discharge a number of responsibilities and his social participation decreases and these will have devastating effect on the well-being of a vitiligo patient.
2. Due to stigma of disease the patients have reported a poor appetite, sleeping excessively or having insomnia, lacking self-worth and having feelings of hopelessness. These symptoms may aggravate stress and depression among them.
3. The social stigma of vitiligo can be difficult to cope. Suffering from vitiligo can lead to poor body image and low self-esteem.
4. Increasing awareness about vitiligo, for example, talking to friends can help patients with the condition to overcome these difficulties. Social support from significant others may also help to the vitiligo patients.

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