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Do young Omani adults with sickle cell disease experience stigma from having the disease?

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Objective The purpose of this study was to assess the level of psychological, sociological and health-related stigmas among young Omani adults with sickle cell disease (SCD).

Methods This study was a descriptive quantitative design study. The sample was 40 young adults with SCD selected from University of Nizwa. A convenience sampling approach was used to recruit the participants.

Results The findings from the study revealed that the young Omani adults with SCD experienced psychological stigma (61%) from the disease with feelings of depression, anger, anxiety, and worries due to frequent complications from SCD. Also, the findings suggested that the Omani young adults experienced societal stigma (50%) from having the disease. In addition, the findings indicated that a large percentages of the respondents suffered from health-related stigma (80%). The results revealed a statistically significant difference ($p = 0.001$) in the psychological stigma scores. Similarly, the results elicited a significant difference in the societal stigma scores. Furthermore, there was also a statistical significant difference in the health-related stigma scores ($p = 0.001$). The mean score for HRS (18.40 ± 5.39) was higher than the normal; suggesting high level of health-related stigma experienced by the participants.

Conclusion The findings revealed that young Omani adults with SCD reported psychological stigma from the disease with feelings of sadness, anger, anxiety, and worries due to frequent complications from SCD. Also, the findings suggested that majority of respondents felt isolated from their families, friends and had trouble getting along with friends due to frequent complications. Also, the disease limited them from participating in social activities and felt that people had avoided them due to their illness. Finally, the findings indicated that the respondents reported health-related stigma due to the physical problems from having SCD and which impeded them from performing activities of daily living.

Key words Psychological stigma, sociological stigma, health-related stigma.

Introduction

Sickle cell disease (SCD) is an autosomal recessive inherited disorder and one of the most common genetic conditions worldwide.[1] It affects mainly people of Afro-Caribbean, Middle Eastern, and Asian origins.[6] Many adolescents and young adults with SCD are challenged by a myriad of complex psychosocial issues, which may be triggered or exacerbated by stigmatization.[2] The magnitude of social stigma and the potential for associated psychosocial adjustment issues in young adults with SCD can be explained within the context of psychological, social, and cultural implications. The literature highlighted that it is significant to understand the psychosocial implications of living with SCD and the adaptation threats in children and adolescents with SCD.

Stigmatization is the process of identifying an attribute of a person or group and associating the attribute with a stereotype that negatively labels or brands another in a way that is perceived as disgraceful by society.[2,9,10] More specifically, health-related stigma (HRS) refers to a form of devaluation, judgment, or social disqualification of individual based on HRS. [2] Stigmatization is increasingly becoming a major public health issue for patients with SCD that is receiving more attention as it adds a burden on individuals and families affected by SCD.[16,17] There is minimal information in the literature about SCD and HRS. Stigma evokes negative attitudes and feelings and usually results in discrimination of the person or institution in various walks of life. This level of stigma can lead to unjust disadvantages for the stigmatized, including direct discrimination on the job, in schools, and within families and may impact the receipt of timely and quality health care.[13,14,15] HRS can have a deleterious affect across the lifespan of individual being stigmatized. Individual with chronic diseases such as chronic obstructive pulmonary disease and chronic pain also face health-related stigmatization. They may feel exiled from the healthier world and feel disgraced due to health encounters and lack of support by providers, friends, family, the community, and the work place.[12, 21,22]

Stigma's possible impact on SCD outcomes is important to the degree that feelings of shame and guilt reduce psychological well-being, inhibit social engagement, and create difficulties in social roles and interpersonal relationships.[23] It is likely that individuals living with SCD disease who perceive stigma about their condition are at increased risk for negative self-evaluations, loss of self-esteem, anxiety, and social withdrawal all of which can have a deleterious impact on health behavior and health status.[24,25] Efforts to study associations between stigma and SCD outcomes have been hindered by the fact that there are no widely used, validated instruments that measure SCD-specific stigma. This inhibits what is known about actual perceptions of stigma among patients and constrains the ability of investigators to make causal connections between stigma and the high rates of psychological symptoms (depression and anxiety) that have been reported in individuals living with SCD.[11,20]

A study was conducted on Nigerian patients with SCD to assess the psychosocial impact of sickle cell disorder on their daily life. [11] The sample was 408, which consisted of 194 males and 214 females. The findings showed that many suffered from psychosocial stigma due to the society attitudes towards them. Also, nearly half number of participants indicated feelings of depression; however, feelings of anxiety and self-hate were much less. The study suggested the needs for more awareness in the community that would positively impact the lives of patients with SCD.[4]

A cross-cultural study on the psychosocial aspects of SCD in the United Kingdom (UK) and Nigeria.[3] It indicated that the patients in the UK and Nigerian patients experienced psychosocial issues due to greater number of pain episodes of longer duration, with more frequent visits to accident and emergency departments compared with those in Nigeria. The Nigerian patients, however; applied more psychologically active coping strategies such as distraction to deal with their sickle cell pain in the community, which significantly impacted on their psychological health. These suggests factors including beliefs, personal factors that help relieving symptoms experienced from chronic pain.

Another quantitative study was conducted to identify the psychosocial stressors of young adult patients with SCD in Cameroon. The findings of the study reported that young adults had difficulty coping with SCD.[23] The findings revealed that health-related stressors such as "degree of clinical severity" displayed the highest median score (2.0), while familial stressors showed the lowest (0.8). Being female, married, with low education level, an additional affected sibling and low direct income were significantly associated with specific stressors' categories reported by patients with SCD.

In the USA, a study assessed the Social and Cultural Context of Coping with SCD.[5] The study shed the light on the importance of the social context to disease management and adjustment. The social factors affected coping with SCD as described in the study were tensions that often arise from ethnic class, power differences between care providers and patient's family members, cultural values, economic resources or hardship, social identity. These factors possessed hardship on individuals with SCD to overcome the debilitating aspects of the illness; which in turn, generated feelings of guilt, shame, and anxiety that impeded or undermined effective coping.[5]

A qualitative study was done on 10 Canadian mothers of African and Caribbean descent to explore their experience of raising a child with SCD.[13] Mothers commonly reported several daily coping challenges: fear of their children's death, separation anxiety, loss of control over life, helplessness, and loneliness/isolation. SCD stigma as a result of racism contributed to social isolation, and prevented families from mingling with other families in the community. All mothers perceived racism as a salient factor that hindered receiving adequate SCD health-related care.

A quantitative study at University of North Carolina was conducted to assess the HRS in young adults with SCD.[7] This study has identified two primary factors contributed to stigma that negatively influenced self-care behaviors and overall health outcomes: the experience of painful crises and parental behaviors, specifically overprotective behaviors. HRS as reported in this study can have detrimental effects on the lives of individuals and families living with SCD that is worth noting.

A study was conducted to assess the perception of young adults with SCD concerning stigma resulted from living with SCD.[15] The study results showed that young adults faced many challenges while living with SCD due to frequent pain episodes and complications. These, in turn, negatively influenced their daily living to maintain self-care and interrupted the relationship with family, work, and their social roles; which had adversely impacted on their quality of life.[15]

Significance and rationale for the study

Stigma contributes to a hidden burden in young adults with SCD that may result in adverse health outcomes. Stigma in SCD may lead to a myriad of physical, psychological, and social problems and its impact on those aspects was not well-studied in the literature. Very few studies that have examined stigma in SCD and the findings from those suggested a significant negative impact of stigma on patients with SCD that is worth identifying and studying. Generally, there is a dearth of studies that have explicitly assessed the influence of stigma on SCD-related health outcomes.[19] In Oman, SCD is a very common hematological problem and contributes to increased mortality and morbidity rates in the country.[18] According to MOH, 6% of Omani population are affected by SCD. Oman Annual Health Statistics report (2010) highlighted that the prevalence of SCD has increased from 86 to 141 cases per 10,000 Omanis from 1995 to 2005. SCD has many complications that effect all aspects of children's life, which include the physical, psychological, social, and mental.[23] The impact of the disease on the physical aspect was well-studied in the literature; however, the impact of the disease on the psychological, social health and whether SCD contributes to feelings of stigma in the young adults remain understudied.[25] Also, the magnitude of HRS and the potential for the associated psychosocial adjustment issues in young adults with SCD was not well-understood in the Omani population, hence this research was conducted. Therefore, the overall objective of this study was to: (1) assess the extent to which the young Omani adults experience stigma; (2) identify the level of psychological, sociological, and HRSs among young Omani adults with SCD; (3) examine the association between age, gender, marital status, and stigmas.

Materials and methods

Design

This study is a descriptive quantitative study using a survey technique to assess the level of stigmas among young Omani adults with SCD.

Sample and setting

Forty Omani young adults with SCD (Students at Nizwa University) were selected to participate in the study. The participants recruited from different colleges from the university and were different in their study level (Year 1–4).

Research tool

Self-Administered Social Stigma Questionnaire developed by King et al[11] was adopted for the study. The tool was made up of 2 parts. *Part I*: consists of 4 items related to demographic data of the respondents. *Part II*: is further divided into three sections: *Section i*: consists of 9 items related to psychological stigma. *Section ii*: consists of 9 items related to sociological stigma. *Section iii*: consists of 9 items related to HRS. The tool was slightly modified and was translated into Arabic before distributing to the respondents. The new tool was piloted on five participants who were not included in the study. Reliability of the tool showed > 0.7.

Ethical approval

Approval before conducting the study was obtained from Ministry of Health, Oman and from the Dean of Pharmacy and Nursing College at the University of Nizwa. In addition, participants were given an information sheet in Arabic to read and those who agreed were asked to sign in a consent form prior to fill in the questionnaires. The participants were informed that their participation in voluntary and that they can withdraw any time. They were also informed that their data will be confidential and no personal data will be reported or presented in the future.

Data analysis

The data were analyzed by SPSS (version 24, Chicago, IL). Initially, a descriptive analysis was performed to ensure that adequate numbers or responses were available for each variable that were included in the analyses and to check for missing values. Variables with missing values were excluded from the analyses. A statistical value $p \leq 0.5$ was considered significant. One sample *t*-test was used to analyze whether the subjects scores in the psychological, societal, and HRSs were different than the normal scores. The data were presented in means, SD, and percentages of different variables.

Generally, normality assumptions for all psychological and health-related scores were met as confirmed by non-significant results of Shapir–-Wilk test (>0.05). There were no outliers in the data, as assessed by inspection of the boxplot. However, the normality assumption for the societal scores was violated (Shapiro–Wilk test <0.05). Data correction was not required as the societal scores had a mean of zero and good skewness (-1 < skewness < 1). Kurtosis was in the good or acceptable range (-2 < kurtosis <2).

Results

Demographic data of the respondents

Forty young adults were recruited for the study. The majority of the respondents (85%) were between 19 and 24 years. The participants were between the age 25 and 30 years and very few were between 31 and 35 years of age. The mean age of the participants (*M* = 28, SD + 2.5). Most of the respondents were females (87.5%) and very few male participants (12.5%). 65% of the respondents were single and 35% were married.

Psychological stigma

Generally, the findings of the study revealed that 60% of young adults with SCD reported stigma due to having SCD and it caused them to have negative emotions and feelings. The results indicated that 64% reported feeling of sadness from having the disease and its complications. 67% of the respondents reported anger from experiencing frequent disease complications. The findings also suggested that, 55% were anxious about their health and 70% of them had worries about what would happen to them in the future.

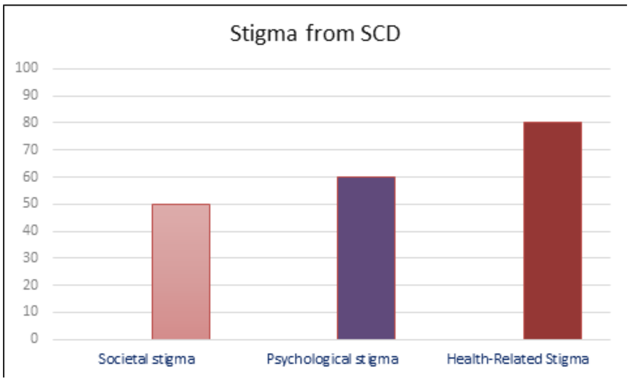

Fig. 1 **Stigma among Omani young adults from having SCD.**

A one sample *t*-test was run to determine whether the psychological stigma score in recruited subjects was different to normal as defined as a psychological score of 9. The higher the psychological scores, indicating high level of stigma in the subjects. The results revealed a statistically significant difference of 3.6 [(95% CL, 2.63- 5. 71), *t* (39) = 3.6, *p*.0.001, *d* = .57] in the psychological stigma scores. The mean psychological stigma score (18.67 ± 6.36) found to be higher than the normal psychological scores of 15; which suggests that the participants have psychological stigma from having SCD.

Sociological stigma

The findings also revealed that, young Omani adults with SCD reported social stigma (50%). The respondents reported that 52% of them felt that disease isolated them from their families, friends, and the community and that 50% had trouble getting along with friends due to frequent disease complications. 65% reported that the disease limited them from participating in social activities and 45% felt that people had avoided them due to their illness. However, 70% of the respondents disagreed that they felt discriminated due to their illness.

A one sample *t*-test was run to determine whether the societal stigma score in recruited subjects was different to normal as defined as a societal score of 9. The higher the societal scores, indicating high level of stigma in the subjects. Similarly, the results elicited significant difference of 6.9 [(95% CL, 4.34–9.50), *t* (39) = 5.4, *p*.0.001, *d* = 0.85] in the societal stigma scores. The mean societal stigma score (21.92 ± 8.07) was higher than the normal societal scores of 15.

Health-related stigma (HRS)

The findings on HRS indicated that the majority of the respondents reported severe HRS (80%) due to the physical problems from having SCD; which impeded from performing activities of daily living. The findings revealed that 94% got easily tired and 73% had difficulty doing simple house-hold tasks because of their health condition. 79% of the respondents had low immunity and experienced frequent infections. Most of the respondents (90%) had trouble sleeping due to frequent pains and other disease complications. Due to frequent pain and hospitalization, 85% had interrupted work and could not work effectively. Generally, 70% of the respondents reported that they would have better life without having SCD.

A one sample *t*-test was run to determine whether the HRS score in recruited subjects was different to normal as defined as a HRS of 9. The higher the health-related scores, indicating high level of stigma in the subjects. There was also a statistical significant difference of 3.4 [(95% CL, 2.67–5. 12), $t\,(39) = 3.9, p.0.001, d = .67$] in the HRS scores. The mean HRS score (18.40 ± 5.39) was higher than the normal HRS scores of 15; suggesting high level of social stigma experienced by the participants.

A chi-square test was run to assess the association between age, gender, marital status, and stigma. There was a significant association between gender and psychological stigma; females reported higher feelings of depression from having SCD ($X^2 = 10.612, p = 0.014$); were worried to tell people they have SCD [$X^2\,(3) = 7.492, p{=}0.05$; felt angry when having pain ($X^2 = 3.96, p = 0.02$); felt angry due to disease complications ($X^2{=}\,8.229, p = 0.04$); and felt worried about what will happen to them in the future ($X^2 = 17.143, p = 0.001$).

The results also revealed a significant association between age and psychosocial stigma [$X^2\,(2) = 3.48, p = 0.1$; adults less than 24 years reported feelings of depression from having the disease more than older adults ($X^2{=}\,7.487, p = 0.2$); felt angry due to frequent disease complications ($X^2 = 10.595, p{=}0.12$); felt worried about what will happen to them in the future than older adults ($X^2 = 11.722, p = 0.05$).

In addition, the results suggested a significant association between the marital status and stigma. Single adults reported higher level of societal stigma ($X^2{=}\,4.336, p = 0.1$) and health related stigma ($X^2 = 3.663, p = 0.05$) than married adults. However, there was no significant association between psychological stigma and marital status ($X^2 = 3.663, p = 0.07$). It was found that there was no significant association between age and societal stigma ($X^2 = 2.704, p = 0.6$) and between age and health related stigma ($X^2 = 2.67, p = 0.7$).

Discussion

The obtained finding was consistent with other studies.[3] The study found that (62%) of young adults with SCD reported psychological stigma from the disease and that nearly half number of participants indicated feelings of depression; however, feelings of anxiety and self-hate were much less (25%).

The present study findings are similar to other studies[17,18] that assessed the level of stigma among young adults with SCD and assess their perception concerning the impact of the disease on health stigma. The results also revealed that young adults reported HRS from having SCD. They faced many challenges and experienced physical stigma while living with SCD; which negatively impacted their quality of life. The studies also highlighted that one of primary factors that negatively influenced health care outcomes in patients with SCD was experiencing HRS.

In the current study, we found that age, gender, and marital status was significantly associated with stigma. Female adults reported higher psychological stigma than males. This could be due to frequent physical pain experienced by females; that could have impacted their psychological well-being. The findings are supported in other studies.[26] The findings also revealed that single and young adults reported higher level of societal and HRS. To our knowledge, this is the first study in the middle-east that examined the association between age and stigma. However, marriage adults reported less stigma may be due to the psychological support and care received continuously from spouse.

Conclusion

The aim of this study was to assess the psychological, societal. and HRSs among young Omani adults with SCD in Oman. Omani young adults with SCD (*N* = 40) were recruited for the study. The findings from the study revealed that the young Omani adults with SCD reported psychological stigma from the disease with feelings of depression, anger, anxiety, and worries due to frequent complications from SCD. Also, the findings suggested that the Omani young adults experienced societal stigma from having the disease. Majority of them felt isolated from their families, friends and the community and had trouble getting along with friends due to frequent disease complications. Also, the disease limited them from participating in social activities and felt that people had avoided them due to their illness. Finally, the findings indicated that a large percentages of the respondents suffered from HRS and many reported severe stigma due to the physical problems from having SCD and which impeded them from performing activities of daily living. Most of the respondents reported fatigue, had difficulty doing simple house-hold tasks, had low immunity and experienced frequent infections. In addition, most of them had interrupted sleep pattern due to frequent pains and other disease complications; which consequently impacted on their work effectiveness and resulted in low quality of life.

Stigma contributes to a hidden burden of SCD that may result in psychological, social, and adverse health outcomes in young adults with SCD; which is worth to be recognized and treated. Therefore, it is very essential to design a multilevel intervention to reduce feelings of psychological, social, and HRSs in patients with SCD. Interventions may focus on support for the affected individuals to enhance their self-esteem and rebuild their self-confidence, counselling with SCD, changing behavior, cognitive behavior therapy interventions may be required to help mitigate the HRS in patients with SCD, as well as considering interventions to help improve health-related quality of life in young adults with SCD. In addition, various combinations of approaches may be appropriate to enhance resilience in response to stressful disease complications and minimize vulnerability to stigmatization. Furthermore, more awareness in the Omani community is required to provide support to those people and possibly reduce the negative feelings experienced from having the disease. Finally, more screenings need to be done in the community to identify the cases and refer them to mental health institutions for early interventions and treatments.

Study limitations

The study used a convenience sampling method that limited the representatives of the sample. The sample size was very small and the sample was collected only from one setting; therefore, the generalization of the findings may not be possible.

Recommendations

It is suggested to replicate the study with more sample size. Also, it is recommended to replicate the study on other settings and cultures.

Conflicts of Interest Disclosure

No conflicts of interest

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