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Relationship between Self-Stigma and Quality of Life among Patients with Schizophrenia

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Abstract

Introduction: Individuals who are diagnosed with severe mental illness (SMI) such as schizophrenia have always been viewed publicly as being hazardous, violent, aggressive and unpredictable. Their awareness of the fact that they are being discriminated against and stereotyped results in an intense feeling of being devalued by the society, which is referred to as Self-stigma [1,2].

Purpose: The study aims to estimate the relationship between Self-stigma and the quality of life among patients diagnosed with Schizophrenia.

Methods: Descriptive cross sectional design was utilized.

The study was conducted at two settings: inpatient Psychiatric department of Tanta University and Neurology, Psychiatry, and Neurosurgery center. Both hospitals are under the supervision and the direction of the ministry of higher education.

A convenient sample of 200 patients with schizophrenia was examined for the study.

Tools: Two tools were used to collect data for this study: Internalized Stigma of Mental Illness Inventory (ISMI), and Quality of life Scale.

Results: It was revealed that there was a statistically noteworthy negative correlation between self- stigma and quality of life among patients diagnosed with schizophrenia.

Conclusion: Higher self-stigma is linked with poor quality of life among patients with schizophrenia.

Keywords: Self-Stigma; Quality of Life; Assessment

List of abbreviations: SMI: Severe Mental Illness; QOL: Quality of Life

Introduction

Stigma has been labelled and summarized as the process of social deterioration of a person, and is associated with feelings of shame, alienation, disgrace, and social seclusion [1]. People with severe mental illness (SMI) such as Schizophrenia have long been categorized and pre-judged by the public as being dangerous, violent, and they are lead to an intense feeling of being discriminated against and devalued by large social groups [2,3], which in turn, is referred to as self-stigma or internalized stigma, because of their awareness of stereotypes and discrimination [3].

Self-stigma has a grave impact on all aspect of life and accordingly, the recovery process in patients with schizophrenia. It affects patients' ability to positively confront their mental illness because of the internalized feeling of guilt, embarrassment and inferiority to others and therefore, rather suppress those feelings [4,5]. In addition to being demotivated to seek their medical or health care, which results in less cooperation in the treatment and hinders their progress in turn. Therefore, patients may experience deterioration of their symptoms, which in turn causes serious social problems for the patient and the community surrounding them [6].

Additionally, several studies have found that Self-sigma have potential negative impact on quality of life QOL [7-10]. QOL is a multi-dimensional underlying concept proposed to reveal the overall functioning and well-being of the patient in different aspects of life. Self-stigma can greatly affect the diagnosed patient's ability to perform (mainly due to long-term cognitive dysfunction and symptoms of the diseases) or function proficiently in marriage, partnership and fulfill parental roles and life demands in general

[10]. Higher rates of self-stigma are also connected to high levels of depression, social anxiety, low self-esteem, demotivation, worse social functioning, less social support and avoidance of coping [11]. This may lead to avoidance, isolation from friends and family, escapism, and ultimately results in social isolation [12].

Moreover, some sociodemographic data as age, gender, ethnicity, awareness of mental illness, employment status, living conditions can be associated with the development of self-stigma [13]. For example; unemployment status can influence on one's sense of autonomy, competence and relatedness, increase risk of developing a negative, inferior self-image; such poor self-evaluation may, in turn, negatively impact health functioning and quality of life [14].

Therefore, understanding the relationship between Self-stigma, Quality of Life and Socio-demographic characteristics is key for providing healthcare givers with insights and new perspectives to the component of self-stigma, which correlates with QOL [15]. Additionally, the degree to which self-stigma causes or exacerbates poorer outcomes among people with mental illness has important implications for mental health services and policy. For example, to what degree should mental health programs and interventions aimed at improving the quality of life of people with mental illness concentrate on perceptions and experiences of self-stigma, as opposed to other clinical or psychosocial factors? Similarly, should governments expect to achieve widespread improvements to quality of life by prioritizing efforts aimed at reducing self-stigma? And, lastly, should quality of life be employed as an outcome measure to assess the effectiveness of self-stigma interventions? [16]. Hence, the present study aims to assess the relationship between self-stigma, quality of life and sociodemographic data among schizophrenic patients.

Research Question

What is the relationship between Self-stigma and quality of life among patients suffering from Schizophrenia?

Methodology

Study Design and Sample

Descriptive cross-sectional research design was employed for current study. The study was conducted at two setting: 1- The inpatient Psychiatric department of Tanta University with a capacity of (31) beds divided into two wards for males (17beds) and two wards for females (14beds). 2-The Neurology, Psychiatry, and Neuro-surgery center with a capacity of (28) beds divided into one ward for males (18beds) and one ward for females (10beds). Both hospitals are under the supervision and direction of the ministry of higher education. A convenient sample of 200 patients with Schizophrenia (100 from each setting), who were available during the time of data collection. The inclusion criteria were: 1-age from 18 to 60 years, from both sexes and diagnosed with Schizophrenia. According to DSM5 diagnostic criteria, the patients are ones who passed the acute stage and are able to communicate and ones who had stayed in hospital for not less than 2 months. The exclusion criteria were severe acute symptomatology and comorbidity with substance abuse, organic brain disease and severe somatic disease, <18 years of age, and intellectual disability.

Tools of the Study

The data of the study was collected using two tools

Tool I consist of two parts

Part I: Internalized Stigma of Mental Illness Inventory (ISMI)

It was developed by Ritsher *et al.* (2003) [17]. It is composed of 29 items divided into five subscales namely: alienation (six items), stereotype endorsement (seven items), discrimination experience (five items), social withdrawal (six items) and stigma resistance (five items). Each group of items was rated on four points Likert scale ranging from: strongly disagree (0) to strongly agree (3), except for the items of the stigma resistance subscale, the score was reversed. All the subscale scores were calculated the higher the scores the greater the experience of the internalized stigma. A score less than 29 indicates a low stigma, a score ranging from 29-58 indicates moderate stigma, while a score more than 58 indicates a high stigma.

Part II: Socio-demographic and clinical data questionnaire:

A- It was developed by a researcher and it includes:

Socio-demographic characteristics, namely age, sex, occupation, level of education, marital status, place of residence and cohabitation.

B-Clinical characteristics of the study patients that includes the duration of their illness, number of previous psychiatric hospitalization and way of last hospitalization.

Tool II: "Schizophrenia Quality of Life Scale (SQLS)":

The scale was developed and tested for validity and internal reliability by Wilkinson *et al.* (2000), and demonstrated good internal consistency [18]. The scale was divided into three subscales addressing different dimensions regarding the impact of Schizophrenia

on the quality of life. It includes psychosocial functioning which covers various emotional issues, motivation and energy, which address various problems of motivation and activity, side effects which includes issues that occur due to side effects of medications. The scale comprises 30 statements to be answered on five points Likert scale type, ranging from: "Never" (0) to "Always" (4). Some questions in the motivation and energy domain (12, 13, 15, 20) have reversed scores that ranges from "Never" (4) to "Always" (0). Higher scores indicate perceived poor quality of life, while lower scores indicate good quality of life.

Procedure

Prior to data collection, an official letter was sent from the dean of the faculty of nursing addressing the director of the Psychiatric department of Tanta university hospital and Neurology-Psychiatry and Neurosurgery center to request their permission and cooperation for data collection.

Ethical Considerations

Informed agreement was obtained from the participants after explaining of the purpose of the study. Confidentiality of their obtained information was maintained, respecting the participant's right of withdrawal at any time during the data collection period.

After that, three tools were translated into the Arabic language by the researcher and back translated. Results showed that the back translation were similar with the original one.

Content validity was carried out by a group of five experts in the psychiatric medicine and nursing fields, The viewers were asked to rate the fit of the translated items according to a five-point scale (0 to 4, where 0 = 0 completely fit and 0 = 0 completely unfit) and the needed corrections were done accordingly.

The validated tools were then tested for their reliability on a group of 20 Schizophrenic patients and Cronbach alpha was used and found to be 0.806, and 0.672 respectively for tool I, II that represent highly reliable tools. Study procedure was revised and approved by the ethical Committee of the Faculty of Nursing and Faculty of Medicine Tanta University.

Pilot Study

A pilot study was carried out on a sample of 12 schizophrenic patients who were selected randomly after obtaining their oral and written consent to participate in the study. Those patients were excluded later from the actual study sample. The pilot study proved the applicability of the study tools.

Actual study

During the actual study, a survey of all hospital wards was done through reviewing all patients' charts in order to identify those who were meeting the inclusion criteria. The form of the study tools was then explained to the patients. Each selected patient was interviewed individually by the researcher using the study tools (tool I,II). Each interview lasted around 45-60 minutes according to the patient's attention, concentration, willingness to co-operate or talk. Patient's clinical data were double checked from their clinical charts. Data collection was completed over a period of 8 months starting from 15-5-2018 to 15-1-2019.

Statistical Analysis

The collected data was organized, tabulated and statistically analyzed using SPSS (software statistical computer package version 20). For quantitative data, mean and standard deviation were calculated. For qualitative data, the number and percentage distribution was calculated. Frequency tables and cross tabulations with percentages were used to illustrate the result of categorical data and tested by chi square (χ 2). Correlation analysis: Pearson correlation is used to test nature and strength of relation between three quantitative/ordinal variables. Chi square was used as test significance. Significance was adopted at p values <0.05 for interpretation of results of test of significance.

Results

Table 1 illustrates the distribution of the studied schizophrenic patients according to their socio-demographic characteristics. It was found that 64% of patients were males, and 36% were females. The highest percentage of the studied patients had age range between 40 to <60 years represent 46.5% and only 13.5% had age \geq 60. The table also presents the residence of the studied patients, denoting that 66.5% of them live in an urban area, while 33.5% were from rural areas. Regarding their level of education, it appears from this table that 29% of the studied patients were illiterate, 21.5% of them can only read and write, 18.5% had basic education, 22% had secondary education, while the lowest percentage of the studied patients (9%) had university and higher education. As for the occupation, 47% of the studied patients were manual workers, while the professionals represent 10.5%. Nearly three quarters of the studied patients (72%) were married, while 28% were unmarried. The majority of the studied patients (62%) live with their family, and only 38% of the patients live alone.

| | Patient with Schizophrenia | | |
|---|----------------------------|---------|--|
| Demographic data | Number (N=200) | Percent | |
| Sex | | | |
| Male | 128 | 64 | |
| Female | 72 | 36 | |
| Age | | | |
| 20-<40 | 80 | 40 | |
| 40-<60 | 93 | 46.5 | |
| ≥ 60 | 27 | 13.5 | |
| Residence | | | |
| Rural | 67 | 33.5 | |
| Urban | 133 | 66.5 | |
| Education | | | |
| Illiterate | 59 | 29.5 | |
| Read and write | 42 | 21 | |
| Basic education | 37 | 18.5 | |
| Secondary education | 44 | 22 | |
| University and higher | 18 | 9 | |
| Marital status | | | |
| Married | 144 | 72 | |
| Unmarried | 56 | 28 | |
| Occupation | | | |
| Unemployed | 38 | 19 | |
| Manual work | 95 | 47 | |
| Employee | 46 | 23 | |
| Professional | 21 | 10.5 | |
| Co-habitation | | | |
| Alone | 76 | 38 | |
| With his or/ her family | 124 | 62 | |
| Duration of illness (in years) | | | |
| <5 | 55 | 27.5 | |
| 5-10 | 49 | 28,5 | |
| ≥ 10 | 96 | 44 | |
| Frequency of hospitalization(s) | | | |
| 1-<4 | 60 | 30 | |
| 4-<7 | 40 | 20 | |
| ≥7 | 100 | 50 | |
| Way of last hospitalization | | | |
| Voluntary way | 74 | 37 | |
| Involuntary way | 126 | 63 | |
| Table 1: Distribution of studied subjects according to their | | | |

Table 1: Distribution of studied subjects according to their socio-demographic and clinical characteristics. (N=200)

Concerning duration of illness, more than two fifth of the studied patients (44%) had illness duration more than 10 years, whereas 27.5% had a duration of illness less than 5 years with a mean 9.2 + 3.8 years. It is apparent also from the table that the majority of the studied patients (63%) were admitted to the hospital against their will, and the rest of them (37%) were admitted voluntary in the last hospital admission. Regarding the number of hospitalization there, half of studied patients were admitted from 1 to 3 times to the hospital, 35.0% were admitted more than 7 times, 30% were admitted from 1 to less than 4 years, and 20 % had been hospitalized from 4 to less than 7 years with a mean of 6.4+2.7times.

(Figure 1) Illustrates the distribution of the studied patients by their level of self-stigma , it was noted that nearly two thirds of the studied patients (63%) had high level of insight, and 31% had moderate level of stigma , while only 6% had low level of stigma.

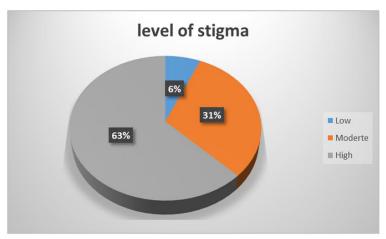


Figure 1: Distribution of the studied patients with Schizophrenia by their total level of Self-stigma

(Figure 2) Shows the distribution of the studied patients by their level of quality of life, more than half of the studied patients 57% had poor quality of life level, 30% had moderate quality of life level, while only 13% had high level of quality of life.



Figure 2: Distribution of the studied patients with schizophrenia by total level of their Quality of life

(Table 2) Revealed that here was a statistical significant negative correlation between stigma and quality of life (p=0.04). Higher levels of stigma are linked to decreased quality of life levels.

| Study Variables | Self-stigma | Quality of life | | |
|-----------------|-------------|-----------------|--------|-------|
| | R | P | R | P |
| Self-stigma | | | -0.241 | . 004 |
| Quality of life | -0.241 | . 004 | | |

Table 2: Correlation between Self-stigma and Quality of life among studied patients. (N=200)

(Table 3) Demonstrates that there was a statistical significant relation between self-stigma and patients' age and frequency of hospitalization. There is no statistical significant relation between self-stigma and the other sociodemographic variables as sex, occupation, marital status, employment, residence, duration of illness and way of previous hospitalization.

| Characteristics | Mean±SD | Z /X ² | P |
|--|--|-------------------|--------|
| Age in years: 20-<40 40-<60 >60 | 52.13±4.21 52.77±6.60 50.74±5.40 | 4.111 | 0.001* |
| Sex: Male Female | 53.58±4.14 52.26±6.43 | 1.366 | 0.172 |

| Marital status Married Unmarried | 52.50±5.32 52.60±6.16 | 0.486 | 0.627 |
|--|--|-------|--------|
| Residence: Rural Urban | 52.41±5.55 52.67±6.23 | 0.010 | 0.992 |
| Educational level: Illiterate Basic education Secondary education University or higher | 52.52±5.09 54.42±8.14 51.35±5.12 | 1.036 | 0.596 |
| Employment Unemployed Employed | 54.71±6.19 51.63±5.57 51.85±5.57 | 2.430 | 0.297 |
| Cohabitation Alone With family | 54.15±5.08 52.03±6.50 | 0.820 | 0.412 |
| Duration of illness (In years) <5 5-<10 >10 | 52.03±5.50 54.03±4.56 53.03±3.76 | 0.011 | 0.993 |
| Frequency of hospitalization 1-<4 4-<7 >7 | 50.13±4.53 51.23±4.66 54.04±6.50 | 4.366 | 0.001* |
| Way of last hospitalization Voluntary Involuntary | 55.43±5.60 52.03±6.50 | 0.486 | 0.627 |

Table 3: Relation between the total Self-stigma level and demographic data

(Table 4) Shows that there was a statistical significant relation between quality of life and cohabitation. There is no statistical significant relation between quality of life and the other sociodemographic variables as sex, occupation, marital status, employment, residence, duration of illness and way of previous hospitalization.

| Characteristics | Mean±SD | Z /X ² | P |
|--|--|-------------------|--------|
| Age in years: 20- 40- >40 | 14.13+4.21 15.77+6.60 16.74+5.40 | 0.011 | 0.993 |
| Sex: Male Female | 13.58+4.14 12.26+6.43 | 1.366 | 0.172 |
| Marital status Married Unmarried | 15.50+5.32 17.60+6.16 | 0.486 | 0.627 |
| Residence: Rural Urban | 12.41+5.55 12.67+6.23 | 0.010 | 0.992 |
| Educational level: Illiterate Basic education Secondary education University or higher | 13.52+5.09 14.42+8.14 17.35+5.12 | 1.036 | 0.596 |
| Employment Unemployed Employed | 13.71+6.19 11.63+5.57 12.85+5.57 | 2.430 | 0.297 |
| Cohabitation Alone With family | 14.15+5.58 12.23+6.50 | 4.820 | 0.001* |
| Duration of illness (In years) <5 5- >10 | 12.22+5.50 13.03+4.60 15.03+7.40 | 0.011 | 0.993 |

| Frequency of hospitalization 1- 4- >7 | 12.43+3.50 13.33+5.62 11.03+5.53 | 1.366 | 0.172 |
|---|--|-------|-------|
| Way of last hospitalization Voluntary Involuntary | 12.23+6.50 14.33+6.40 | 0.486 | 0.627 |

Table 4: Relationship between the total Quality of life level and demographic data **Z/X2(Chi-Square)**

Discussion

The results of the current study revealed that the majority of the studied patients experienced moderate to high level of internalized stigma and this is consistent with the results of Esalam Da *et al.* (2018), which found out that just under half of the study patients with Schizophrenia experienced moderate to high level of internalized stigma [19]. Similarly, Boyd *et al.* (2014) found that half of participant's experienced high levels of internalized stigma [20].

This result might be attributed to the negative Egyptian societal stereotypes about mental illness, which is derived from culture values and media coverage of mental illnesses that has been consistently and overwhelmingly negative and imprecise. This emphasizes a biased image of patients with mental disorders as threatening individuals who endanger society. Accordingly, the internalizing of shame, blame, guilt, and fear of discrimination are experienced. Another possible explanation for this result might be the insufficient health education and intervention programs provided for psychiatric patients and their families, regarding the ways to cope with mental illness stigma [21].

However, this finding is contrasting with findings of preceding studies done in Nigeria 2011. The sternness of mental illness is most probably the reason for the inconsistent findings [22]. The variation of the severity of mental illness - given that the current study has been done on patients suffering from Schizophrenia, a more severe form of mental illness, while the formers have been done on less severe forms of mental illness - is reflected in the lower rates of stigma within less severe forms of mental illness [19,21].

Regarding the score of quality of life, the finding of the present study indicates that more than half of the studied schizophrenic patients had poor quality of life, while about thirteen percent of them had good quality of life. This goes in line with a study done by Ayenalem, Tiruye (2017) in Ethiopia, which revealed that, a high percentage of the studied participants were proven to have low level of quality of life [23,24]. In the same direction, a study conducted in Egypt by Oka A (2011) to demonstrate the impact of insight on quality of life among patient with schizophrenia results, indicated that the majority of the patient had poor levels of quality of life [25].

This result might be attributed to high level of perceived stigma among schizophrenic patients and the feeling of rejection from the surrounding society. Another possible explanation could be the devastating impact of schizophrenia on the patients' thoughts, feeling and behavior. This impact leads to feelings of distress, lack of control, choice and autonomy, low self-esteem and confidence, diminished activity, a sense of hopelessness and demoralization. All of this in turn, may have a significant negative effect on QOL [25,26].

The present study found a statistically significant negative relation between stigma and quality of life among patients with schizophrenia. In other words, the increasing level of stigma leads to decreasing quality of life. An interpretation of this finding could be due to several factors. First, stress resulting from stigma, which is associated with lower self-esteem and consequently the increase of hopelessness among patients with schizophrenia [19]. Second, Patients who self-stigmatize themselves more due to their mental disorder are inclined to regard themselves as inferior, unapt at fulfilling their needs and duties, limited in their skills and general life functioning and incapable of succeeding in life. This brings about reduced hope, demotivation and self-acceptance, having an impact on the overall perspective of life and eventually the apparent actual QOL. Lastly, self-stigma influences the patients' contentment about their life and their performance of the daily living activities, therefore, affecting their feeling of independence and influencing their quality of life, eventually [26].

Prior research seem to strongly support the relationship between the internalized stigma and quality of life; showing that, primarily within chronic samples, the more internalized stigma increases, the more the quality of life decreases [20,27,28].

This findings also correspond with a study by Alem *et al.*, (2018), which revealed that self-stigma and QOL were inversely associated and that stigma worsen QOL of people with mental illness [23]. Other studies revealed that internalized stigma could have considerable negative impacts on individual functioning, including reduction in quality of life and self-esteem, and increase in hopelessness [29-32].

Regarding the relation between self-stigma and the sociodemographic data of the studied schizophrenic patients, the present study found that there is significant association between self-stigma and patients' age, as the young age group have high level of stigma than older. This may be because there are more understanding of their friends and more social interactions and focus on self-attributes at a younger age [33]. This goes in line with a study conducted by Rohit Garg *et al.*, which revealed that significantly higher stigma scores were reported in younger patients than older ones [34]. Furthermore, self-stigma was found to be linked to a great extent with the frequency of hospitalizations. This proves to be logical, as those who have experienced more hospitalizations are more likely to have

been subjected to discrimination from others and to have experienced more rounds of the disorder. The finding aligns with the results of a study conducted by Holubova, *et al* (2016), who found significant correlation between self-stigma and number of hospitalization [35]. However, this result contradicts a study conducted by Gerlinger *et al* (2018), which indicated that there is no relationship between any sociodemographic variables and self-stigma among schizophrenic patients [27].

Concerning the relation between quality of life and sociodemographic data of the studied schizophrenic patients, the present study found that there is significant association between quality of life and cohabitation. The patients who live alone have lower quality of life than the patients who live with family members. This may be due the social, emotional or psychological support provided from family members for the patients, which may help to mitigate the impact of mental illness on different aspects of their life. These findings are in agreement with a study conducted by Pinho LG, Pereira A., Chave. (2017) and concluded that patients who lived alone have lower quality of life than patients who live with family members [36].

In the final analysis, the finding of this study indicates the fact that self-stigma influences negatively the quality of life of people diagnosed with mental illness. Individuals, who view themselves as more stigmatized, valued their QOL as lower and vice versa. However, it is impossible to explain accurately the relationships between these two variables within the cross-sectional design of this study.

Conclusion and Recommendations

From the present study, one could conclude that the majority of schizophrenic patients often have high self-stigma and poor quality of life. Self-stigma is associated negatively with mental disorders, specifically to quality of life among patients with schizophrenia. Thus, patients with higher levels of insight into their mental illness reported poor psychosocial functioning and emotional well-being.

From the results of the present study, one can recommend the following:

Psychoeducational programs to schizophrenic patients, which focus on self-stigma and QOL, is essential to help in improving abilities and performance, and also enhance the quality of patients' life. In addition, future interventions and research could be directed towards helping patients diagnosed with schizophrenia to overcome their negative notions and find practical and positive ways to deal with themselves and their surroundings. Thus, allowing them to accept mental illness and have fewer devastating effects.

Limitation

The generalizability of the results is considered the only limitation of this study, because of the relatively small sample size and the participants who were recruited through convenience sample. Another limitation is that a cross sectional study, cannot explain the relationship between variables, which it turn might have affected the results.

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