IRBAS www.irbas.academyirmbr.com October 2023
International Review of Basic and Applied Sciences Vol. 11 Issue.4

Internalized Stigma of Mental Illness, Coping Styles and Perceived Stress of Caregivers of People Diagnosed with Psychiatric Illness

SHAMSA BATOOL
MSCP Graduate, Department of Psychology
Forman Christian College (A Chartered University).
Email: shamsabatool007@gmail.com
Tel: +92 312 4708091

ELIZABETH SCHWAIGER
Associate Professor, Department of Psychology
Forman Christian College (A Chartered University).
Email: elizabethschwaiger@fccollege.edu.pk
Tel: +92 (42) 992 31581

ABIA NAZIM
Associate Professor, Department of Psychology
Forman Christian College (A Chartered University).
Email: abianazim@fccollege.edu.pk
Tel: +92 (42) 992 31581

Abstract

This study aimed to assess the level of perceived stress, internalized stigma, and coping styles among caregivers of patients diagnosed with psychiatric illness. A total of 160 adult participants from eight hospitals in Lahore were selected via convenience sampling. Following informed consent, participants were asked to fill a questionnaire consisting of the Urdu versions of the Internalized Stigma Scale (Ritsher et al., 2003), Coping Styles Scale (Zaman, 2015), and Perceived Stress Scale (Chan, 2013). Regression analysis was employed to predict the impact of internalized stigma and problem-focused coping styles on perceived stress among caregivers of psychiatric patients. The results indicated moderate levels of perceived stress and a significant positive relationship between stigma and stress, as well as a negative relationship between problem-focused coping styles and perceived stress. These results indicate an unrecognized need among caregivers of those with psychiatric illness.

Keywords: *Internalized Stigma, Coping Styles, Perceived Stress, Psychiatric Illness, Mental Health, Patients, Diagnosed, Caregivers, and Family Members.*

Introduction

The prevalence of psychological disorders is on the rise, affecting approximately one individual in every fourth family (WHO, 2003). There are several factors, such as lack of awareness, knowledge, poverty, social pressure/stigma, cultural biases, religious beliefs, and limited information about mental illness, contribute to heightened stress experienced by those grappling with mental health issues. Individuals diagnosed with different mental disorders endure perceived stress and internalized stigma by employing diverse coping styles to cope with their challenges. However, family members and primary caregivers of

these patients face their own set of difficulties, including perceived stress, internalized stigma, and coping mechanisms. In Pakistan, caregivers dedicate themselves to their loved ones without any financial compensation due to cultural and religious values, while in European countries, caregivers are hired to take care of their dear ones (WHO, 2003). Apart from caregivers' nature of service (paid or unpaid), several caregivers themselves experience psychological and mental health issues, such as stress, anxiety, depression, lack of social interaction, interpersonal conflicts, emotional problems, psychological distress, and social pressure. They do not aware to handle and overcome their stress (Ribé et al., 2018; Wolff et al., 2016).

Literature Review

Internalized stigma of mental illness develops when the patient and his family face societal pressure, social stigmatization, and labeling. The caregiver then absorbs all that negativity into himself (Rüsch et al., 2009). Several research studies have demonstrated that caregivers of those with psychiatric diagnoses develop stigma towards themselves.

Zisman-ilani, Levy-Frank, and Hasson-Ohayon (2013) studied the parents of people who were suffering from severe mental illness and their level of stigma. A total of one hundred ninety-six parents of children with psychiatric illness were chosen through purposive sampling. The results revealed that around one-third of parents were stigmatized and mostly stereotype endorsement was reported. Due to the negative stereotype stigmatization, the parents started to avoid social gatherings and prefer staying at home. It was also reported that the parents also started to think of themselves less as individuals as compared to other parents who have “normal” children; They started to devalue themselves and disrespect themselves.

In China, a qualitative study was conducted to measure the internalized stigma of family caregivers of patients diagnosed with schizophrenia (Wong, Kong, Tu, & Frasso, 2018). Eight families of the patients were selected and the results of this research indicate that the parents of the patients with mental illness were facing emotional burden and emotional distress and impairment in daily life due to the illness of their dear ones. Moreover, it was reported that both parents and patients were socially stigmatized due to the illness of their dear ones (Wong, Kong, Tu, & Frasso, 2018). Interpretive Phenomenological Analysis was conducted in Iran to measure the nature of stigmatization of the family members of the people suffering with bipolar disorder. The results of this study revealed that most of the people commonly reported that they perceived negative judgment by the people and society as the people had not enough knowledge about the nature and severity of illness. The feelings of shame were the second common theme reported by the family members, faced due to the illness of their close family members suffering with bipolar disorder. These studies indicate that it is not only the patients who faces the rejection and discrimination from the people and society, but the caregivers were also being rejected, shamed and discriminated against by the society (Shamsaei, 2013).

Another research study was conducted in China among the patients diagnosed with psychotic symptoms and their caregivers (Chen et al., 2016). Forty-four pairs of patients and caregivers within the age range of 15 – 45 were selected. Regression analysis along with correlation was administered to check the connection between internalized stigma, psychological disturbances and affiliated stigma due to the 1st episode of psychotic symptoms. The results of this study revealed that the caregivers were socially stigmatized which increased the psychological disturbances and distress such as anxiety, MDD and stress and lessen their level of quality life and enhance their burden whereas the patients with first episode of psychosis symptoms such as schizophrenia, drug abuse and schizoaffective diagnosis were stigmatized from society because people did not like to have relationships with such people and did not accept them as an individual one. It was also notable that due to lack of knowledge and awareness they did not consult to any psychiatrist earlier stage of disorder (Chen et al., 2016).

In New York, a study was conducted on the patients diagnosed with bipolar disorder. Five hundred caregivers were selected for this study. Correlation, Regression analysis, Bivariate analysis and post hoc analysis were applied. The researchers wanted to assess the internalized stigma and associated features of the illness which caregivers were facing. The finding of this study revealed that females, especially spouses and mothers at early age; more visits of hospitalization; severe symptoms in active phase of bipolar disorder; and lack of social support predicted greater stress and stigma among caregivers of the patients diagnosed with psychiatric illness (Antonio, Haven, Sciences, & Alto, 2007).

Stigma further leads to greater levels of stress in a population that already has much higher levels of perceived stress. A review of 286 research studies found that it is not only the patients diagnosed with schizophrenia disorder who was suffering with multiple problems but the families and caregivers were also facing multiple problems and distress due to the illness of their dear one. The burden and stress were badly affected the family and caregivers and caused significant distress for both of them (Geriani, 2015).

It is also notable that mostly family members or primary caregivers of mental illness sufferers did not know about the nature of their disorder, signs and symptoms of illness and how to treat with such patients. Illiteracy sometimes causes some big loss for the patients and for family as well as increases their stress level (Qadir, Gulzar, Haqqani, & Khalid, 2013).

In India, the researchers conducted a study to measure that how much the caregivers diagnosed with schizophrenic patients were facing the perceived stress due to the illness of the disorder of their dear one and which ways of coping they were using to cope that situation (George, 2015). The findings showed that the primary caregivers of mental illness sufferers had been facing significant perceived stress due to the illness of their dear ones. In this study not any significant correlation was found between stress and ways of coping, although it was found that the negative correlation existed among economically well-established caregivers and stress whereas positive correlation was found in education and age, as level of education and age increases, the level of stress decreases. Most of the people used social support and distracting ways to cope up for stressful situations (George, 2015).

Another study was done in India by Darlami, Ponnose, and Joes (2016), total fifty caregivers were selected by using purposive sampling through descriptive survey method. Results of this study indicated that the psychotic patients were more disturbed due to their illness but the primary family members were also facing their illness, the burden of their treatment, social pressure, stigmatization by society and economic issues. Female especially spouse, were more stressed while dealing with the patients diagnosed with psychotic symptoms and mostly, they used active and passive coping to deal with the stress through using reinforcements, religious thinking or they suppressed the stress. It was found significant correlation among stress and other demographic such as ethnicity, religion, education, age, relationship with patient, economic status, type and onset of the illness and marital status. It was also indicated that almost above 70% caregivers were mentally distressed and needed psychological services as well.

In Pakistan, cross-sectional research was done with the 100 caregivers (most of them were females) of the patients diagnosed with psychiatric illness. The researchers wanted to check the quality of life of the caregivers and family burden in the form of depression and anxiety. For this standardized screening measurement tools were used. The findings of this research discovered that few participants reported that they do not have any psychological or emotional disturbance in the form of depression and anxiety, whereas the majority of the participants reported that they were facing psychological and emotional disturbances as well as financial burden and their quality of life was disturbed but they were doing well with these problems by practicing different coping styles to move on in their daily life (Imran at al., 2010).

Research was conducted in Pakistan, in Rawalpindi city (Armed Forces Institute of Mental Health) on the caregivers of people suffering with mood disorders and schizophrenia disorder. The purpose of this study was “To examine the factors associated with caregivers’ burden in individuals providing care to family

members suffering from serious mental illness" (Siddiqui & Khalid, 2019). For measurement standardized assessment tools were applied and one hundred and twenty participants were selected by adopting purposive samplings. By nature, it was a qualitative and cross-sectional research design. The findings showed that the as long as someone lives with the patient reported higher burden and stress as compare to others who spend less hours with the patient. With the reference of higher education, unmarried, belonging to higher socio-economic status, living in urban areas reported that they experienced fewer burdens and that's why their psychological health was good as compare to others (Siddiqui & Khalid, 2019).

Hypothesis

1. The sub scales of Internalized stigma of mental illness: Alienation, stereotype endorsement, discrimination experiences and social withdraw, and a subscale of coping styles that is problems focus coping, would be positive predictors of perceived stress of caregivers of patients diagnosed with psychiatric illness.

Theoretical Framework

This research is grounded in the "Stress Coping Model of Internalized Stigma" as developed by Rüsch and his colleagues to overcome the effects of stigma by explaining how stigmatized individuals experience stress and utilize coping mechanisms (Rüsch et al., 2009).

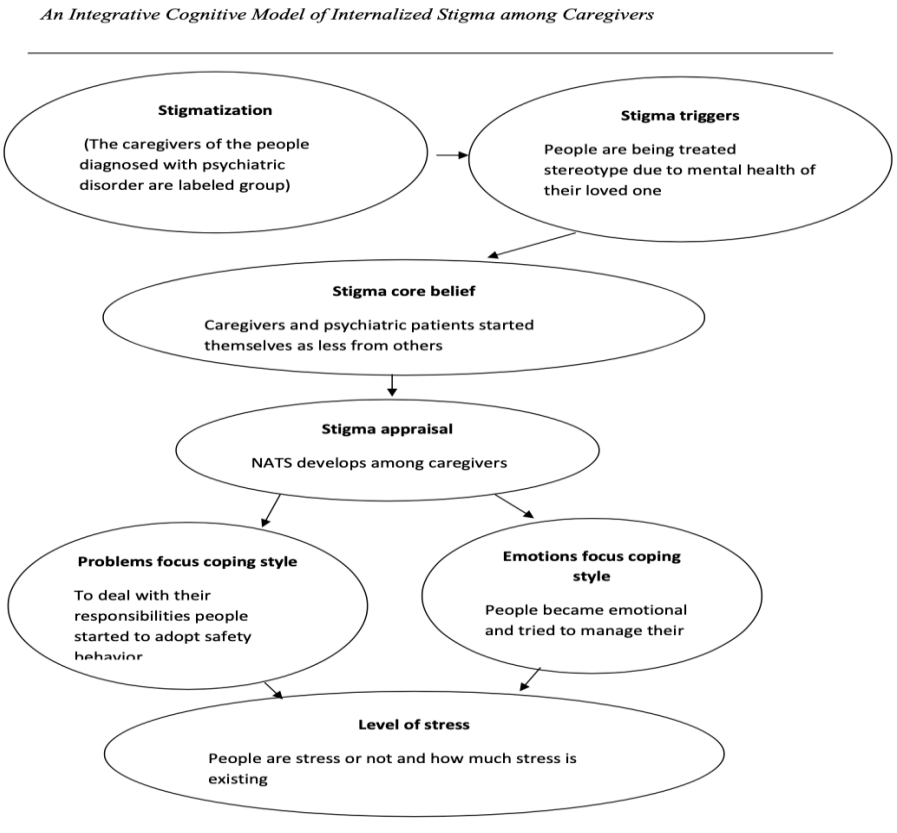

Figure 1. A Cognitive Model of Internalized Stigma among Caregivers

Caregivers are significantly affected by this stigmatization because they play a vital role in the treatment, management, and recovery of individuals with psychiatric illnesses. To manage their stigmatization and fulfill their responsibilities, caregivers adopt various coping styles, including engaging in problem-solving approaches and others grapple with emotional imbalances (Rüsch et al., 2009). Figure 1 provides a schematic of the model.

When people become ill or diagnosed with any psychiatric illness the then they are treated as a stereotyped group and labeled as less than others. Caregivers are also stigmatized according to the illness of their loved ones. Caregivers play the most important role in the life of the patients diagnosed with psychiatric illness, such as the treatment, management and recovery of those patients, and therefore identify with the loved one's condition. Those people who are labeled start to think of themselves as less of a person first because of others' perspectives, then they start to devalue or disrespect themselves. This develops the core negative automatic thoughts (Beck, 1979) among those people. The caregivers adopt different types of coping styles to manage their stigmatization and their responsibilities such as some people started to find out the problems and tried to resolve their problems whereas some people emotionally imbalance and started to manage their emotions regarding the perception of stigmatization. Those people are also stressed as compare to others whose are not stigmatized (Rüsch et al., 2009).

Method

Participants

Previous researches supported that the total number of participants were selected for this research was 160 adult participants. The participants who were selected for this study was family members (parents, siblings, spouse and children) or primary caregivers (uncle, aunt cousin or others) of the patients diagnosed psychiatric illness. Data was collected via convenience sampling (a type of non-probability sampling) to focus on the caregivers of the people diagnosed with some psychiatric illness, that are schizophrenia spectrum disorder, somatic symptoms disorders, bipolar disorder, post traumatic disorder, obsessive compulsive disorder, substance related disorders, depressive disorder, anxiety disorders, dissociative disorders and others. The family members were living with the patients diagnosed with psychiatric illness from any psychiatrist, psychologist or medical officer and these caregivers were living with the patients for previous two weeks, one month or more and spend maximum time by looking after them. The caregivers who were diagnosed with psychiatric illness or any physical illness were not participating and the hired and paid caregivers were not the part of this research. The data was selected from Lahore hospitals, from the Punjab Institute of Mental Health, Ganga Ram Hospital, Services Hospital, Mayo Hospital, Jinnah Hospital, and Fountain House were visited to collect data.

Material and Methods

First of all, the informed consent of the participants was taken from the caregivers of the patients diagnosed with psychiatric illness. A list of demographic variables was given to the participants to take basic information of the caregivers of the patients diagnosed with psychiatric illness.

Internalized Stigma of Mental illness

Initial developed by Ritsher, Otilingam, and Grajales (2003), the Internalized Stigma Questionnaire includes 29 items. The Test-retest correlation was good (0.92, $P<0.05$), and internal consistency of ISMI was very high (Cronbach's Alpha = 0.90) and construct validity was good (Ritsher et al., 2003). ISMI divided is into 5 subscales that are Stereotype Endorsement, alienation, social withdraw, discrimination experience, Stigma Resistance. The ISMI is on 4-point Likert and some items such as item No.7, 14, 24,

26, 27 had been reversed coding (Ritsher, Otilingam, & Grajales, 2003). This scale was translated into Urdu version by Faiza Rasool, Nashi Khan Ph.D. and Dr. Rukhsana Kausar Ph.D.

Coping Styles Scale

The CSS (Coping Styles Scale) is a self-report assessment, consisting of twenty- two items on a five-point Likert-type scale. CSS was divided into two major groups (i) Problem focused coping and (ii) Emotion focused coping. The psychometric properties of CSS were high (Cronbach's alpha = .87, split-half and test-retest reliability of Problem focused coping were .84, and .80, respectively) and Emotion focused coping (i.e. 89, .80, & .74, respectively; Zaman, 2015).

Perceived Stress scale

The perceived stress "measures the degree to which situations in one's life are appraised as stressful" (Cohen & Williamson, p. 33). The Perceived Stress Scale (PSS) was introduced by Chan and La Greca (2013). PSS consists of ten items on a five-point Likert scale, whereas, Item No. 4, 5, 7, and 8 had reverse scoring. The age range of this scale was eighteen to sixty-five and older. In this scale "the feelings, emotions and thoughts are asked with the reference of last month" (Chan & La Greca, 2013). PSS could be used for both gender (male and female). PSS was widely used scale it was translated into many languages and was translated into Urdu language by Aneeqa Mariam in 2011. PSS-10 had construct validity and 0.78 alpha reliability was found. The PSS version 10 was a very less to very often and scoring range was zero to forty which means that the more score indicated high level of perceived stress and less score leads minimum perceived stress (Chan & La Greca, 2013).

Procedure

For this study, the approval was sought out from the university's IRB Board. Permission from the authors of the scales has been taken via email for using their scales to collect data. The permission was taken from the Hospital Institutions where data was collected. The participants were given the verbal or written informed consent in which the purpose and nature of the study was explained in detail. The participants were assured about the privacy and confidentiality of their data. The participants were also educated that they have right of withdraw from study at any position of the study during the research. It was also told them that after the completion of this research, the results of this study would be share if they wanted to know about it. The participants would be provided therapy in PIMH or BAHAM Institute, if they needed or they would be suggested for therapeutic session. The verbal consent was taken by these professional psychologists regarding to the reference to caregivers' therapeutic sessions.

Analysis

Characteristics of The Sample

The demographic variables are presented in detail in Table 1 and Table 2 (N=160). Table 1 illustrates the frequency and percentage of categorical demographic variables such as gender, marital status, religion, education, profession, background, relationship, living duration, diagnosis, diagnosis by. Table 2 shows the mean, standard deviation, and range of age, duration of the disorder, and looking after of the participants.

Table 1: Descriptive Statistics of Categorical Demographic Variables (N=160)

Variables	*f*	%
Gender		
Men	87	55.6
Women	73	54.4
Marital status		
Unmarried	66	41.3
Married	86	53.8
Widow	6	3.8
Divorced	2	1.3
Religion		
Islam	149	93.1
Christian	11	6.9
Education		
Uneducated	29	18.1
Metric	13	8.1
F.A	15	9.4
B.A	43	26.9
Masters	60	37.5
Profession		
House wife	43	26.9
Unemployed	11	6.9
Student	17	10.6
Employees	16	10.0
Business Owner	20	12.5
Others	53	33.01
Background area		
Lahore	106	66.3
Rural areas	13	8.01
Other cities	41	25.06
Relationship		
Parents	40	25.0
Siblings	52	32.5
Life partners	21	13.1
Children	19	11.9
Other relatives	28	17.5
Living duration		
Less than 1 month	26	16.3
More than 1 month	134	38.8
Diagnosis		
Schizophrenia	30	18.8
Bipolar	18	11.3
Depressive disorder	22	13.8
Obsessive compulsive disorder	10	6.3
Somatic symptoms disorder	9	5.6
Post-traumatic stress disorder	1	0.6
Substance related disorder	16	10.0
Anxiety disorder	6	3.8
Mental disorder	22	13.8
Do not know	26	16.3
Diagnosed by		
Psychiatrist	120	75

Medical doctor	19	11.9
Psychologist	21	13.1

Note. f=frequency, %=percentage

The mean age of the participants was (35.36) and the Standard Deviation (13.12), whereas the mean of the duration of the disorder was (94.45) and standard deviation was (104.16). The mean of looking after the patients diagnosed with psychiatric illness by their caregivers/family members was (1.23 years) and the standard deviation was (.63). the mean of looking after of the patients diagnosed with psychiatric illness was (1.23) and standard deviation was (.63).

Table 2: Descriptive Statistics of the Continuous Demographic Variables

Variables	M	S.D	R
Age	35.36	13.12	50
Duration of the disorder	94.45	104.16	594
Looking after	1.23	.63	4

Note. M= Mean,S.D=Standard Deviation, R= Range; all variables reported in years

Table 3 shows the number of items and Cronbach's Alpha of each of the scales used in the study. Of note, four scales were lower than the expected level for good reliability (a = .70).

Table 3: Cronbach's Alpha Reliability of Internalized Stigma of Mental Illness, Perceived Stress Scale and Coping Style Scale (N= 160)

Variables	No of items	α
Internalized stigma of mental illness	29	.90
Internalized stigma of mental illness Alienation	6	.74
Internalized stigma of mental illness Stereotype Endorsement	7	.74
Internalized stigma of mental illness Discrimination Experience	5	.68
Internalized stigma of mental illness Social Withdraw	6	.68
Perceived stress scale	10	.75
Coping style scale	22	.77
Problems focus coping styles	8	.75
Emotion focus coping style	14	.62

Note, a= Cronbach Alpha

Main Analysis

Preliminary analyses showed no outliers or collinearity. The residuals were normally distributed, therefore, the main analysis was computed. Simple regression analysis was computed to evaluate the degree of prediction of the coping styles scale and the internalized stigma of mental illness subscales on perceived stress. The regression analysis was significant ([F (5, 154) = 12.23, p<.001]. It is presented in Table 5. The model showed that problem focus coping style has significant negative prediction whereas internalized stigma of mental illness alienation, stereotype endorsement, discrimination experience and social withdraw showed significant positive prediction on perceived stress of individuals. The $R2$ value of .26 revealed that the predictors explained 26% variance in outcome variable (F [5, 154] = 12.23, p<.001). Social endorsement of internalize stigma of mental illness positively and problems focus coping style negatively predicted perceived stress of caregivers of patients diagnosed with psychiatric illness (β = .27, p<.05; β = -.16, p<.001, respectively).

Table 4**:** Multiple Regression Analysis of Perceive Stress Scale, Coping Style Scale and Internalized Stigma of Mental Illness on Caregivers of Psychiatric Patients.

	B	SEB	β	T	P
PSS	8.41	6.64	---	2.31	.02*
ISMIA	.21	.24	.10	.87	.38
ISMISE	.46	.19	.27	2.43	.01**
ISMIDE	.19	.29	.07	.67	.49
ISMISW	.34	.22	.14	1.52	.13
PFCSS	-.21	.09	-.16	-2.37	.01**

Note. *p<.05. **p<0.01. SEB= Standard Error of Beta, ISMIA= Internalized Stigma of Mental illness Alienation, ISMISE= Internalized Stigma of Mental illness Stereotype Endorsement, ISMIDE=Internalized Stigma of Mental illness Discrimination Experience, ISMISW= Internalized Stigma of Mental illness Social Withdraw, PFCSS= Problem Focus Coping Style Scale

Discussion

The current study was conducted on the caregivers or family members of the patients diagnosed with psychiatric illness because it was not only the patients who could be suffering but also their caregivers and family who were also psychologically distressed and stigmatized. The present study examined caregivers' or family member's psychological distress, perceived stress, internalized stigma of mental illness and the way they adopted to cope with the stress of having a loved one with a psychiatric diagnosis.

The hypothesis of the study was supported. The results showed that there was 26% variance that all these subscales predicted the perceived stress of the caregivers of patients diagnosed with psychiatric illness. Additionally, the alienation, discrimination experience, stereotype endorsement and social withdraw of internalized stigma of mental illness, has significant positive prediction on perceived stress, whereas problem-focused coping styles has significant negative prediction on perceived stress of the caregiver of the patients diagnosed with psychiatric illness. This is an important finding as it provides an avenue for helping caregivers to mitigate the burden of perceived stress through problem-focused coping.

There was not any previous research found that described the predictions of internalized stigma of mental illness and coping styles on perceived stress of the caregivers of the people diagnosed with psychiatric illness; however, Shamsaei (2013) reported that the caregivers started to hide their relationshiisp with the patient diagnosed with psychiatric illness because of society stigma, stereotype behavior, isolation, discrimination, sham and psychologicl distress, and their level of stress increases day by day.

Limitations and Future Directions

The limitations of the current study include the sampling strategy, lack of diversity of the sample, and the lower reliability of several subscales. Convenience sampling of caretakers and family members of only those hospitals in Lahore reduces the ability to generalize the findings of the study to other areas of Pakistan. Moreover, given the week to non-significant findings, it is possible that the study lacked power. Future researches should consider other areas of the country and larger sample sizes to address this limitation. There were two subscales (emotion-focused coping, internalized stigma of mental illness stigma resistance) these subscales reliability was very low and therefore these subscales could not be included in the analyses. These limited findings should be addressed in future researches.

Lack of awareness of psychiatric illness as it is most commonly considered as a mental disorder that is highly labeled and stigmatized by society, so there is need to work to create the awareness among people. Such kind of awareness could be not just for the patients and caregivers but also for other relatives and common people so that the stigma of mental illness can be reduced.

The implication of current study highlights the importance to provide some basic knowledge and informative skills to the primary caregivers of patients especially diagnosed with psychiatric illness, in this way perhaps they may avoid from maltreatment and decreased stress of the caregivers, because it is reported commonly and almost everyone knows that the illiteracy and malpractice may increase the anxiety and stress among people. So, to reduce perceived stress and stigmatization faced by the society due to the psychiatric illness of their dear ones, there should be some training programs to be held in hospitals and rehabilitation centers; this will be more beneficial for both caregivers and patients as well.

Findings of the current study revealed that there is a need to the make awareness and promotion of mental health of the people for caregivers as well as for the patients of psychiatric illness and to take part in the prevention of the mental illness in the society so that they can learn to be resilient by using more coping styles in a constructive way to deal with their stressful situations.

Conclusion

This study examined the impact of internalized stigma and coping styles on perceived stress among caregivers of patients diagnosed with psychiatric illness. The findings supported the hypothesis that internalized stigma of mental illness positively and problems focus coping style negatively predicted perceived stress of caregivers of patients diagnosed with psychiatric illness. In the context of Pakistan the implications of this study are multifaceted. First, caregivers experience moderate levels of perceived stress on average. Second, their level of perceived stress is partially predicted by internalized stigma. Finally, problem focused coping can have a mediating effect on these levels. This is a population that is overlooked. The people they care for need care, support and psychological services, but the caregivers themselves also need care, support and psychological assistance.

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