



CAREGIVERS' BURDEN, PERSONALITY, INTERNALISED STIGMA AND PSYCHOLOGICAL MORBIDITY -AN EXPLORATORY STUDY AMONG SPOUSES OF INDIVIDUALS WITH MENTAL ILLNESS

Psychology

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ABSTRACT

The primary caregiver has to cater to all the needs of an individual with mental illness and it is important to understand the psychological impacts of caregiving. In the present study, the objectives were to determine the perception of burden of the caregivers, their personality pattern, internalised stigma and psychological morbidity. The sample included 27 spouses, between 30-50 years, of individuals with bipolar disorder, major depressive disorder and schizophrenia. The tools administered were NEO Five Factor Inventory, Zarit Burden Interview, Self-stigma among caregivers of mental illness and General Health Questionnaire. Product Moment correlation was used to find the correlation between caregiver burden and internalised stigma, caregiver burden and psychological morbidity and internalised stigma and psychological morbidity. An attempt was also made to find the correlation between personality domains and caregiver burden, personality domains and internalised stigma and personality domains and psychological morbidity. Results indicated that correlation existed among several variables.

KEYWORDS

caregiver burden, personality, stigma, psychological morbidity

INTRODUCTION

Caregiving is one of the most arduous tasks that an individual might have to go through. It is as debilitating as the mental disorder itself. Interest in the topic of caregiver burden grew as the concept of deinstitutionalisation became popular (Kuipers et al, 2004). This topic became even more important in India as the families are considered the primary caregivers here (Chadda, 2001). There is a strong consensus supporting that caring for an individual with disability is **burdensome** and stressful to many family members and contributes to morbidity. Researchers have also suggested that the combination of loss, prolonged distress, the physical demands of care giving and biological vulnerabilities of caregivers may compromise their physiological functioning and increase their risk for physical and psychological morbidity, which leads to increased mortality (Schultz and Beach, 1999).

Researchers later started focussing on several other aspects of his life such as his family interactions, interactions with friends and other family members, his work, his income, his leisure and recreation. However one mediating variable was gradually recognised, that is, the personality of the caregiver. For instance, Studies have indicated that high neuroticism was positively correlated with high caregiver burden and depression whereas individuals who score low on neuroticism are more resilient, rational and calm (Lima and Simoes, 2003).

Another factor which was believed to mediate the relationship between psychological and physical health and caregiver burden is one's feeling of being stigmatised as a result of his association with another stigmatised family member. This is also called Internalised stigma. According to Jones et al, 1984 "Internalised stigma is accepting the discrediting of one's worth conveyed by the society, can occur without the experience of overt mistreatment and can lower a person's sense of self esteem and prestige, because he or she is aware of the threat of censure or rejection." Research conducted in this direction revealed that caregivers with fear of stigmatisation are unable to interact freely with outsiders because of their family member's illness and as a result they reduced their interaction with other members of their community (Ae-Ngibise, et al., 2015; Girma et al., 2012).

The aim of the present study is to assess the personality domain, caregiver burden, internalised stigma and psychological morbidity of caregivers of individuals with major depressive disorder, bipolar disorder and schizophrenia and to find if there exists any correlation among these variables.

METHODOLOGY

Sample

The study was conducted on 27 spouses of individuals having mental illness, namely bipolar disorder (in manic phase), major depressive disorder and schizophrenia (having positive symptoms). All the

caregivers were within the age range of 30-50 years. Only those caregivers were included in the study whose spouses received a confirmed diagnosis of the above mentioned illness on the basis of ICD-10 and were suffering from the mental illness for at least 4 years. All the caregivers had received at least 8 years of formal education and were residing with their spouses for at least 4 years.

Caregivers with any history of psychological illness or substance abuse were excluded from the study. Caregivers whose spouses had other co-morbid psychological illness or any kind of physical illness were excluded from the study.

The caregivers were assessed at the outdoor Departments of various government hospitals.

Tools used in the study

An **information schedule** was prepared to collect certain information about the patient and the caregiver (spouse) as would be relevant for the current research problem.

Neo Personality Five Factor Inventory (NEO FFI) Developed by Costa and McCrae, this scale was used to assess the personality domains of the caregivers (spouses). The reliability coefficient was found to be .86 to .90 for the five scales.

General Health Questionnaire -28 (GHQ- 28) was developed by Goldberg and Hillier in the year 1979 and is used for identifying psychological problems among the general population. GHQ 28 assesses anxiety, somatic symptoms, insomnia, depression and thoughts of harming one's own self. Test-Retest reliability of this scale has been found to be 0.78-0.9 (Robinson and Price, 1982) and the interrater and the intrarater reliability as revealed by Cronbach's alpha was found to be 0.9-0.95 (Failde and Ramos, 2000).

Zarit Burden Interview (ZBI) was used to assess the subjective distress experienced by caregivers of individuals with mental disorder. The psychometric properties of the test indicate that it has a good internal consistency with a Cronbach's alpha of 0.92.

Self-stigma among caregivers of people with mental illness was adopted from the World Health Organisation Family Interview Schedule. 15 items were selected in order to assess the subjective stigma experienced by the caregivers of people suffering from mental illness. This test was first administered in Jimma University Specialized Hospital Psychiatry Clinic in Ethiopia. It assessed the need of a caregiver to hide the mental illness experienced by his family member, to avoid close association with others and if he/she experienced any feelings of shame. Cronbach's alpha for the present test was found to be 0.85.

All the tests (except GHQ 28) were translated to Bengali (the native language) so that the items can be easily understood by those participating in the study. Once the translation was done, the items were rated by two native speakers so that the items can be validated.

A standardised Bengali version of GHQ 28 was already available which was developed by Basu and Dasgupta in the year 1995.

The participants of the study also had to sign a consent form where the details and the purpose of the research were stated.

Statistical Procedure

Statistical analyses were done using IBM SPSS Statistics 21. Product Moment Correlation was used to assess the relationship amongst the variables. 0.05 level of significance were considered as critical level.

RESULTS

(Insert Table 1 and 2)

Table 1.1 reveals the correlation amongst caregiver burden, internalised stigma and psychological morbidity. Results indicated that a significant positive correlation existed amongst all these three variables.

Table 1.2 demonstrates the correlation between personality domains and caregiver burden, personality domains and internalised stigma and personality domains and psychological morbidity. Results revealed that neuroticism has a significant positive correlation with all the three variables namely, caregiver burden, internalised stigma and psychological morbidity. Extraversion and Conscientiousness has a significant negative correlation with psychological morbidity. Agreeableness has a significant negative correlation with caregiver burden, internalised stigma and psychological morbidity.

DISCUSSION

Caregiver burden has a significant positive correlation with internalised stigma. Any individual who perceives himself to be 'stigmatised', because of his association with another individual who has a mental disorder, is likely to consider the second individual as a burden. Qualitative analysis of the responses to the test items indicate that individuals who felt that their mentally ill family members can cause them embarrassment in social situations refrained from social interactions and this led to perceive their family member as burden for whom they are unable to socialise. This shows how the two variables 'caregiver burden' and 'internalised stigma' have a mutual connection between them. This connection can work in the reverse way as well.

As these individuals feel 'burdened' and 'stigmatised', they become susceptible to developing various psychological problems like sleeplessness, tension headache, feelings of helplessness and hopelessness, low mood and so on. With time these problems become so predominant that their feelings of burden further enhance (as they have to take care of themselves as well as their spouse) and that in turn increases their feelings of discrimination. Research also supports this fact that 'affiliate stigma' (Self- stigma) increases caregivers' psychological morbidity (Elafros et al, 2013). This further intensifies the symptoms of the individual undergoing mental disorder. What could be ascertained from this research study is these three variables (caregiver burden, internalised stigma and psychological morbidity) together form a cycle where increase in one of these factors increases the others as well.

Some personality factors have also been found to have significant relationship with the above mentioned three variables. For example, Neuroticism was found to have a significant positive relationship with caregiver burden, internalised stigma and psychological morbidity. Individuals who scored high on this scale tend to emotionally unstable and a worrier by nature which leads to unrealistic thoughts (Lima and Simoes, 2003). Furthermore such individuals are more likely to be preoccupied with only the negative aspects of different situations. As a result when such individuals have a spouse with mental illness, they primarily focus on the problems that they are facing because of their spouse which results in a feeling of burden. Similarly they are fixated on thoughts like how negatively the society will perceive them which strengthens their feeling of stigmatisation. This in turn makes them more vulnerable to developing psychologically morbid conditions. Research findings have also shown that high neuroticism leads to increased caregiver burden and feelings of depression (Melo et al, 2011).

Corrina et al, 2011 found that extraversion has a positive impact on physical and mental health. The present research has also obtained similar findings. 'Extravert' people can socialise with others more easily. Socialisation, as it is already known, helps people to learn new ways in which they can deal with their problems. Similarly they also learn whom they can approach for help. Socialisation also helps people to get this insight that their problem is not so 'uncommon' after all. They are more motivated to join peer groups and support groups than are people who score low on the domain of Extraversion. This reduces their feelings of burden, internalised stigma and contributes to their psychological well being.

Individuals high in Conscientiousness tend to be very disciplined and organised and practice behaviours that contribute to their well-being (Bogg & Roberts, 2004) and also foster them with a sense of confidence and competence. They are less vulnerable to developing anxiety and depression and hence are more equipped to deal with the burden of caregiving. Since they maintain a disciplined life, they are able to meet the needs of their spouse more effectively and also cater to their own needs.

Individuals with high score in Agreeableness are much more flexible and much more capable of adjusting to a new or difficult situation. Thus it leads to better physical, social and cognitive health (Jerram & Coleman, 1999; Steel, Schmidt, & Shultz, 2008). They can more readily accommodate to the changes in their life which reduces their feeling of burden, stigma (as they can easily accept the difficult situation) and psychological morbidity.

Thus, on the whole, this research study indicates that the personality structure of the caregiver will determine whether the cycle of burden, internalised stigma and psychological morbidity will be strengthened or weakened.

CONCLUSION

This research points out to the need for psychoeducation which should be given to the caregiver at the very onset of his/her spouse's mental illness. The caregivers should also undergo screening tests in order to find out if they are vulnerable to developing psychological disorders. They should also be brought in touch with various support groups and peer groups who can help them to accept and adjust to the difficult situation. Attempts should also be made to enhance the psychological awareness of the community. Finally there is a lot of debate as to whether personality traits are longstanding attributes that are resistant to change or whether they can be modified using therapy. However such research studies do exist which highlighted that personality traits can be changed using Cognitive- behavioural therapy (Clark et al, 2003), mindfulness therapy (Krasner et al, 2009) and social skill training program (Piedmont, 2001).

Table 1.1: Pearson's Product Moment Correlation was used as a statistical measure to assess the relationship between caregiver burden, internalised stigma and psychological morbidity (N=27)

	Caregiver burden	Internalised stigma	Psychological morbidity
Caregiver Burden	1.00	0.664**	0.757**
Internalised Stigma	0.664**	1.00	0.776**
Psychological morbidity	0.757**	0.776**	1.00

Table 1.2: Pearson product moment correlation was used to assess the relationship of all the personality domains with caregiver burden, internalised stigma and psychological morbidity (N= 27)

Personality Domain	Caregiver burden	Internalised stigma	Psychological morbidity
Neuroticism	0.559**	0.622**	0.777**
Extraversion	-0.189	-0.089	-0.408*
Openness	-0.217	-0.280	-0.044
Agreeableness	-0.408*	-0.432*	-0.441*
Conscientiousness	-0.250	-0.188	-0.394*

**- significant at 0.01 level

*- significant at 0.05 level

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