The International Journal of Indian Psychology
ISSN 2348-5396 (e) | ISSN: 2349-3429 (p)
Volume 7, Issue 1, DIP: 18.01.046/20190701
DOI: 10.25215/0701.046
http://www.ijip.in | January- March, 2019

The International Journal of INDIAN PSYCHOLOGY

**Research Paper**

# Factors Associated with Wellbeing in Spouses of Chronic Schizophrenic Patients

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## ABSTRACT

Chronic schizophrenia in a family member is a persistent source of distress to the family and caregivers. An increased number of mental health issues such as anxiety, depression and burden have been reported in the persons involved in caregiving of schizophrenic patients. Sufficient data have been generated to quantify the caregivers' burden and its correlates; but relatively less attention has been paid to the positive aspects such as wellbeing. This study is an attempt to fill this gap and identify a range of factors that are associated with the wellbeing of the spouses of chronic schizophrenic patients. 80 spouses (40 male and 40 female) were sampled from a psychiatric hospital using defined inclusion/exclusion criteria. Following tools were administered to collect the data: Brief Case Record Form, PGI Wellbeing Scale (Verma & Verma, 1989), Indian Disability Evaluation and Assessment Scale (Rehabilitation Committee of Indian Psychiatric Society, 2002), Positive & Negative Syndrome Scale (Kay et al 1987), Burden Assessment Schedule (Thara et al. 1998), Social Support Questionnaire (Nehra & Kulhara, 1987) and Coping Checklist (Rao et al. 1989). Out of an array of processed variables following variables emerged as significantly associated with the wellbeing in spouses of chronic schizophrenic patients - (1) Patients' disability (2) Social support (3) Psychopathology (4) Burden of Care (5) Problem Solving –Coping (6) Emotion Focused - Distraction Positive Coping (7) Acceptance (8) Religion/Faith (9) Denial (10) Problem & Emotion Focused (11) Age of Spouses in years (12) Patients Age in years (13) Age of onset of illness in patients in years (14) Duration of exposure to Spousal illness in years (15) Duration of Illness in Patients in years.

***Keywords:*** *Wellbeing, Spouses of Psychiatric Patients, Social Support, Burden of Care, Families of Psychiatric Patients*

Schizophrenia presents in a widely varied ways across individuals; from a predominantly deficit symptoms to multiple active and florid psychotic symptoms to significant reduction in or excessive motor symptoms. Some of the symptoms can be controlled and managed rapidly

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**Received: January 24, 2019; Revision Received: February 15, 2019; Accepted: February 24, 2019**

resulting in temporary crisis in the persons involved in care and management of afflicted individuals. But in majority of the cases, one or the other symptoms particularly deficit ones continue to persist for years with periodic exacerbations of florid symptoms leading to a continuous source of stress to the family members particularly primary care givers. The persistent stress encroaches upon the health and wellbeing of the persons involved in care and treatment of afflicted individuals. Lowyck, et. al (2004) reported that family members of schizophrenic patients experience burden on a practical, financial and emotional level and the extent of the burden is closely linked to the amount of symptomatic behavior of the patient.

Literature suggests that caregivers of schizophrenic patients are at risk of developing emotional problems. Salleh (1994) found that about 23% of the carers developed neurotic disorders resulting from the stress; nearly half of them had neurotic depression. Provencher (1996) observed that most common negative consequences directly related to the ill relative were the primary caregiver's emotional problems, the disturbance in the primary caregiver's performance of work, and the disruption in the lives of other adults in the household. Wittmund et al (2002) reported that psychiatric patients' partners are at a high risk of developing a depressive disorder. Jungbauer, Mory, and Angermeyer (2002) observed a considerably increased prevalence of depressive disorders compared to the level in the general population. The severity of the patient's disease and the caregiver's mental problems are significant predictors of psychosomatic complaints in parents and spouses.

Hell (1982) examined the personality structures and the well-being of the partners in a sample of 103 married depressive and schizophrenic hospitalized patients. The more phases of illness the spouses had witnessed, the more unattractive, self-controlled and uncommunicative they proved to be and the less irritated and sensitive they were when the patient was hospitalized. Rammohan et al. (2002a) observed that coping strategies of denial and problem solving, strength of religious beliefs and perceived burden were significant predictors of wellbeing in relatives of schizophrenic patients. Strength of religious belief plays an important role in helping family members to cope with the stress of caring for a mentally ill relative. Martens and Addington (2001) indicated that the strongest predictor of psychological well-being in family members of schizophrenic patients was the negative scale of the Experience of Caregiving Inventory (ECI). There was also a significant relationship between poor psychological well-being and short duration of illness. Chen et al. (2004) studied the psychological wellbeing of caregivers of individuals with schizophrenia and factors affecting the caregivers psychological welling. More specifically, quality of life and psychiatric morbidity were used to represent the psychological wellbeing. There was a significant association between the positive symptoms score and the psychological wellbeing of caregivers. Life quality and psychiatric morbidity were affected by caregivers knowledge of schizophrenia and beliefs about the cause of schizophrenia.

Compared to the magnitude of researches on caregivers' burden in psychiatric disorders; less attention has been paid to the study of positive aspects such as wellbeing in caregivers of persons with severe mental illness. The available studies suggest a disruption in wellbeing in spouses of schizophrenic patients; and a few predictors like strength of religious belief, duration of illness have been identified. This study aims at further expansion of the idea of cataloguing significant factors associated with the wellbeing of the caregivers of schizophrenic patients so that appropriate strategies could be evolved to enhance their general wellbeing, quality of life and life satisfaction.

In married psychiatric patients, some spouses desert the patients and seek formal divorce and others do continue to execute the role of primary caregivers; and in the process of caring and with passage of time a few of them would explore and opt for the option of separation. The

studies which exclusively focused on spousal burden in schizophrenia reported greater distress in female spouses (Kumar et al 2005); and even higher distress in literate female spouses (Kumar et al. 2001). The studies have revealed that women experience and respond to stress in distinctive ways compared to men (Helgeson, 2006)). Women's stress response process is both qualitatively and quantitatively different in terms of hormonal profile, activation of the sympathetic, adrenal, medullary and hypothalamic-pituitary-adrenal-cortical response pathways, and in emotional quality. In addition, the nature of women's lives and realities render them at risk for stress-related effects more often than men. Wellbeing bears a significant positive correlation to minimization. Women spouses with mentally ill husbands may feel more comfortable when they are able to minimize the importance of the problem (Cherkil, 2010).

This study was designed to focus on spouses of chronic schizophrenic patients primarily for two reasons. Firstly, there are indications of differential effects of schizophrenic illness across spouses of both the genders. Secondly, there was a high probability of availability of spouses of chronic schizophrenic patients in in-patients facility "Family Ward" of the psychiatric facility where this study was designed and executed.

***Objectives**:*

To find out association of following variables with wellbeing in spouses of chronic schizophrenic patients:

a. Socio-demographic and Clinical Variables
b. Psychosocial Disability
c. Severity of Psychopathology
d. Burden of Care
e. Social support
f. Coping Mechanisms

## METHOD

***Setting**:*

The study was conducted at Institute of Mental Health and Hospital (IMHH), Agra. IMHH is a tertiary care hospital with an intake capacity of 818 patients in the in-patients units having a primary catchment area of the State of Uttar Pradesh (UP) for indoor services. Family Ward of IMHH is an open and a short stay ward with an average stay of about 10-15 days. At least one family member/guardian is required to stay in the ward with the patient. It has an intake capacity of 60 patients; and most of the time it remains occupied.

***Sample**:*

80 spouses of chronic schizophrenic patients were sampled from Family Ward of IMHH using following inclusion/exclusion criteria:

1. The patient who met ICD-10 diagnostic criteria for schizophrenia.
2. The duration of continuous illness more than two years
3. No associated other major psychiatric and medical illness
4. Spouses having history of any major psychiatric and medical illness, substance abuse except nicotine and caffeine, subnormality of intelligence were excluded.
5. Only those spouses who were willing and agreed to give informed consent were included.
6. The spouses with at least two years continuous exposure to spousal schizophrenic illness were included.

***Tools:***

Following tools were administered on each spouse:

1. **Brief Case Record Form:** A semi-structured proforma was developed to record pertinent identifying and clinical information regarding patients and their spouses.
2. **PGI Wellbeing Scale** (Verma and Verma, 1989) was used to measure the psychological well-being of the spouses. This is a 20 item scale. The total number of items ticked by the participants makes the total number of wellbeing score. Thus, the range of score on the scale is 0 to 20. The split-half reliability index by using Kudar-Richardson formula is reported to be 0.98 and test-retest reliability index is reported to be 0.91.
3. **Indian Disability Evaluation and Assessment Scale (IDEAS)** by Rehabilitation Committee of Indian Psychiatric Society (2002) was used for measuring psychosocial disability in the patients. It was developed by the Rehabilitation Committee of Indian Psychiatric Society. IDEAS has 4 items: self-care; interpersonal activities (social relationship); communication and understanding; and work. Each item is scored between 0 and 4. The global disability score is calculated by adding the total disability score (i.e. total score of the above 4 items) and the DOI (Duration of Illness score - 1 means a duration of illness < 2 years, 2 for 2-5 years, 3 for 6-10 years, and 4 for > 10 years). Its alpha value was 0.8682, indicating good internal consistency between the items. It has good criterion validity and at face value, the instrument appeared to be measuring the desired qualities. Criterion validity was established by comparing IDEAS with SAPD (Schedule for the Assessment of Psychiatric Disability) which has been standardized in India.
4. **Positive and Negative Syndrome Scale (PANSS)** (Key etal.1987) was used to assess severity of symptomatology. The PANSS consists of 30 items rated on a 7-point scale. PANSS includes positive negative depressive, activation, and autistic preoccupation symptom dimensions. It is most widely used test for assessment of psychopathology in schizophrenic patients.
5. **Burden Assessment Schedule (BAS)** (Thara et al. 1998) was used to assess magnitude of burden in spouses. BAS measures burden in nine areas: (a) Spouse related (b) Physical and mental health (c) external support (d) caregiver's routine (e) support of patient (f) taking responsibility (g) other relations (h) patients' behaviour (i) caregivers' strategy. There are 40 items rated on three point scale. The reliability is 0.80. The validity ranges from 0.71-0.80.
6. **Social Support Questionnaire (SSQ)** (Nehra & Kulhara, 1987) was used to assess psychosocial support for spouses. This scale has 18 items. Each item has four response options, which range from 'no agreement' to 'total agreement'. Seven items are positively worded and 11 are negatively worded. Higher score indicates that more social support is available to the spouses.
7. **Coping Checklist (CC)** Rao et al. (1989) was used to assess coping mechanisms of the spouses. The checklist consists of 70 items in seven subscales categorized in three domains: problem focused, emotion focused and; problem and emotion focused. The retest reliability is .74. It has been validated in a community sample.

***Procedure:***

The prospective patients and their spouses were approached, briefed about nature of the study, screened through inclusion/exclusion criteria, informed consent was sought and above tools were individually administered. PANSS was completed by interviewing the patients. For IDEAS, the information was sought from the spouses and direct observations of the patients were also made. PGI Wellbeing Scale, BAS, Coping Checklist and SSQ were

administered on spouses. The information on Brief Case Records were collected from spouses, patients and available Case Records of the patients in IMHH.

***Data Analysis:***
The data were analyzed in SPSS 11.5 for Windows for computation of descriptive statistics and correlation co-eficients

## RESULTS

***Table- 1: Descriptive Statistics and Correlation Co-efficients with PGI Well-being Scale Scores***

| **Categorical Variables** | | **n (%)** | **Correlation Co-eficients** |
|---|---|---|---|
| Gender | Male | 40 (50%) | -.144 |
| | Female | 40 (50%) | |
| Domicile | Rural | 35 (44%) | -.142 |
| | Urban | 45 (56%) | |
| Socio-economic Status | Low | 32 (40%) | -.030 |
| | Middle | 48 (60%) | |
| Patients' F/H of Psychiatric illness | Yes | 20 (25%) | .029 |
| | No | 60 (75%) | |
| **Continuous Variables** | Mean±S.D. | | - |
| IDEAS | 04.75±01.97 | | **-.628**** |
| Burden of Care | 99.06±16.92 | | **-.721**** |
| PANSS | 63.42±21.49 | | **-.635**** |
| Denial | 04.22±02.03 | | **-.690**** |
| Social Support | 38.43±10.80 | | **.795**** |
| Problem Solving -Coping | 05.92±02.57 | | **.491**** |
| Emotion Focused - Distraction Positive Coping | 04.01±02.54 | | **.451**** |
| Acceptance | 06.25±02.59 | | **.568**** |
| Religion/Faith | 04.86±02.13 | | **.227*** |
| Problem & Emotion Focused | 02.67±01.91 | | **.367**** |
| Age of Spouses in years | 38.41±10.45 | | **.404**** |
| Patients Age in years | 37.91±10.24 | | **.327**** |
| Age of onset of illness in patients in years | 29.96±07.85 | | **.283*** |
| Duration of exposure to Spousal illness in years | 08.09±05.52 | | **.242*** |
| Duration of Illness in Patients in years | 07.90±05.15 | | **.268*** |
| Emotion Focused - Distraction Negative Coping | 01.71±01.75 | | -.014 |
| *PGI Wellbeing Scale* | *08.67±05.42* | | |
| **Significant at .05 level; **significant at .01 level* | | | |

Gender, domicile, socio-economic status, patient's family history of psychiatric illness and emotion focused –distraction negative coping variables were not associated with wellbeing of spouses.

Social support, problem solving coping, emotion focused distraction positive coping, acceptance, religion/faith, problem and emotion focused coping, age of spouse, patients' age,

age of onset of psychiatric illness, duration of illness and exposure were found to be positively associated with wellbeing in spouses.

Disability on ideas, psychopathology, burden of care and denial coping mechanism were negatively associated with wellbeing in spouses of schizophrenic patients.

## DISCUSSION

The aim of the present study was to identify factors associated with wellbeing in spouses of chronic schizophrenic patients. Patients' disability, burden of care, social support of spouses and use of denial coping mechanism have negative impact on the wellbeing of the spouses. The findings are in expected direction.

Psychosocial disability in patients makes them largely dependent on the caregivers even for their activities of daily living. The patients who acquire disability due to schizophrenia demonstrate impaired occupational functioning, negligible social network and impaired communication skills. Such patients pose great difficulty for the caregivers as they have to look after not only the needs of the patients but also would be required to make arrangements for occupational functioning. Researchers reported significant relationship between patients' disability and burden of care (Arun et al. 2018; Gireesh et al 2015).

Wellbeing of caregivers is negatively affected by burden of care. Gupta et al. (2015) observed a strong negative correlation between burden and psychological well-being of caregivers. The caregiving of schizophrenia patients is resource hungry which becomes detrimental to the emotional and physical health of the caregivers. Martens and Addington (2001) reported that the strongest predictor of psychological well-being in family members of schizophrenic patients was the negative scale of the Experience of Caregiving Inventory.

The symptom profile of the patients is also negatively correlated with wellbeing. Pugazhendhi, Kathir & Ravishankar (2018) observed more burden of care with severe symptom profile. In addition, these researchers also reported negative correlation between positive and negative psychopathology and psychological wellbeing of caregivers. A link between burden of care and psychological wellbeing exist as both the state burden of care vis-à-vis wellbeing are contrary to each other.

Denial coping mechanism is negatively associated with wellbeing of spouses. Rmamohan et al (2002b) reported denial coping mechanism as significant predictor of burden in caregivers of schizophrenic patients. Denial is a maladaptive coping mechanism it does not lead to any solution to a problem. The issues triggering denial mechanism continue to exist.

Social support is positively associated with wellbeing of spouses of chronic schizophrenic patients. Perceived social support is also significantly associated with burden of care. In a meta-analysis, Del-Pino-Casado et al (2018) reported that there is a moderate negative association between perceived social support and subjective burden of care. Social support acts as a buffer against stress and burden thereby maintain the wellbeing of caring family members.

Problem Solving –Coping, Emotion Focused - Distraction Positive Coping, Acceptance, Religion/Faith and Problem & Emotion Focused coping mechanisms are positively associated with wellbeing in spouses of schizophrenic patients. Coping is a process that manages the internal and external demands which may be overwhelming on the individual. The use of

adaptive and effective coping mechanisms efficiently manages the problem situation where as inefficient and maladaptive coping mechanisms maintain the stress level and do not lead to effective solutions. Problem solving coping mechanism is considered as optimal. Also, there are coping mechanisms that do not lead to solutions but mitigate the effects of stress in life. Grover, Pradyumna, & Chakrabarti (2015) reported that Indian studies examining use of coping mechanisms by families of schizophrenic patients observed that caregivers adopt a mixture of both adaptive and maladaptive coping strategies to cope with the patient's illness. Some of the studies have reported more frequent use of problem focused coping strategies than seeking social support and avoidance strategies (Kate et al. 2013; Chadda, Singh, Ganguly, 2007).

Age of spouses and Duration of exposure to schizophrenic illness in spouse are also positively associated with wellbeing in schizophrenia. Both the variables are interlinked as with advancing age, the duration of exposure to illness in spouse also increases. The acute and early phase of schizophrenic illness is usually more distressing and overwhelming to the spouses whereas with continued illness, over the period of time, the spouses might have developed acceptance of the situation and coping resources to deal with the adverse situation by finding alternative means of managing financial and other aspects of family life.

## CONCLUSION

The results of the present study suggest that severity of symptom profile, schizophrenic disability, burden of care, coping mechanisms, social support and illness related variables are related to the wellbeing of spouses of schizophrenic patients. In a perspective of positive mental health, an attention on positive aspects of wellbeing of spouses of schizophrenic patients is required. Attempts can be made to promote their wellbeing by encouraging efficient coping mechanisms and proper treatment and rehabilitation of the patients.

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***Acknowledgements***

The authors profoundly appreciate all the people who have successfully contributed in ensuring this paper is in place. Their contributions are acknowledged however their names cannot be able to be mentioned.

***Conflict of Interest***

The authors colorfully declare this paper to bear not conflict of interests

**How to cite this article:** Rathor, D.S, Mohanty, S & Kumar, S (2019). Factors Associated with Wellbeing in Spouses of Chronic Schizophrenic Patients. *International Journal of Indian Psychology*, *7*(1), 418-426. DIP:18.01.046/20190701, DOI:10.25215/0701.046