

Original Article

Quality of Life Determinants in Family Caregivers of People with Schizophrenia: A Quantitative Study from India

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Data for this study was collected at: Thanjavur Medical College Hospital, Thanjavur 613004, Tamilnadu, India

Abstract

Background: Schizophrenia is a chronic, debilitating illness that poses considerable burden on family caregivers who look after people with schizophrenia (PWS). Family caregivers play a crucial role in providing support for people with mental health conditions such as schizophrenia. This has implications for the carers' own mental health as well as their quality of life (QOL).

Aims: This study seeks to ascertain the role played by social support and coping in influencing the quality of life of family caregivers of people with schizophrenia.

Methodology: A quantitative design was used to compare caregivers of PWS with those having general medical conditions. Standardised instruments were administered to both groups in a clinical setting in India using survey methodology.

Results: Findings indicate poorer coping skills and quality of life and lesser social support in the caregivers of PWS. The study also evidences the interaction between social support and coping in influencing QOL in family caregivers.

Conclusions: Our results indicate that it is neither social support by itself nor the overall coping efforts of the caregivers, but the interaction between the two that ultimately determines QOL. It is hence important that psychotherapeutic efforts are directed in a two-pronged effort to simultaneously enhance coping strategies as well as to ensure the provision of adequate social support mechanisms for informal caregivers of people with schizophrenia.

Keywords: Coping; Family caregiving; Schizophrenia; Social support; Quality of life

Introduction

Schizophrenia is a chronic and severe mental disorder that typically begins in late adolescence or early adulthood, and is characterized by profound disruption in thinking, language, perception, and the sense of self, and often includes psychotic experiences, such as hearing voices or delusions (World Health Organisation, n.d.). As in most Asian societies, the family in India is considered to be the "natural" primary caregiver to provide informal care for a family member experiencing chronic mental illness

such as schizophrenia. Religious considerations such as the Hindu belief in 'Dharma' are often the reason why the onus of care provision is shouldered by the family. Informal care is typically provided by either the parents, children, or the spouse and as a family obligation that is based on socio-cultural expectations (Stanley, Mettilda & Bhakyalakshmi, 2016). High levels of caregiver burden have been reported by family members who provide informal care for a relative diagnosed with schizophrenia (e.g., Arun, Inbakamal, Tharyan &

Premkumar, 2018; Kuchhal et al., 2019). Informal caregiving has physical, social, emotional, and financial implications for the family and given the unpredictability and debility associated with schizophrenia often results in an extremely harrowing experience for the caregivers (Stanley, Balakrishnan & Ilangovan, 2017b). Caregivers also experience considerable burden in relation to their own well-being and health (Gupta et al., 2015). The stigma associated with mental illnesses in conservative Indian society is yet another factor that the family has to contend with. It has been reported by family members that friends, relatives or neighbours avoid or treat them differently (Raguram, Raghu, Vounatsou & Weiss, 2004). Higher caregiver stigma is associated with higher psychological morbidity in caregivers (Grover et al., 2017). The family may experience network contraction and condensation, owing to social alienation which may exacerbate the stress experienced due to the lack of adequate social support (Magliano et al., 2002). The availability of social support is hence crucial in terms of understanding the family's overall effort in coping.

Coping is the process of managing demands (external or internal) that are appraised as taxing or exceeding the resources of the person (Lazarus & Folkman, 1984). Several studies from India which have investigated coping strategies used by family caregivers in schizophrenia indicate that a range of both adaptive and maladaptive strategies are used (e.g., Aggarwal, Avasthi, Kumar, & Grover, 2011; Kate, Grover, Kulhara & Nehra, 2013; Nehra, Chakrabarti, Kulhara & Sharma, 2005). Common coping strategies involve consulting Doctors, seeking help from family and friends for practical help and guidance and more frequent use of emotion-focused strategies such as coercive coping and behavioural avoidance by caregivers of PWS (Nehra et al., 2005). Grover, Pradyumna & Chakrabarti (2015) conclude a comprehensive review of caregiving and coping in India by noting that the use of problem-focused or adaptive coping mechanisms, are associated with better caregiving outcomes. Coping strategies used by caregivers and the social support available to them, influence the final appraisal of the

caregiving experience (Aggarwal et al., 2011).

Quality of life (QOL) is an important concept that relates to understanding the overall caregiving experience in schizophrenia. In the context of this study, it brings together the family's perception of burden and stress, their efforts in coping with these as well as the extent of social support that the family perceives as being available. The World Health Organisation considers QOL to be a broad ranging concept affected in a complex way by the person's physical health, psychological state, personal beliefs, social relationships, and their relationship to salient features of their environment. A review of the caregiving literature concludes that physical, emotional, and economic distress negatively affect caregiver's QOL as a result of a number of unfulfilled needs such as, restoration of patient functioning in family and social roles, economic burden, and lack of spare time (Caqueo-Urizar, Gutiérrez-Maldonado & Miranda-Castillo, 2009). Lower QOL in caregivers of PWS has been reported in other studies from different parts of the world (e.g., Ribé et al., 2018) and from India (e.g., Stanley et al., 2017b; Panigrahi, 2014).

This study was planned against this background and seeks to examine the extent to which three key variables (coping, perceived social support and quality of life) are manifested in family caregivers of PWS. We were also interested in understanding the role played by social support and coping in influencing QOL outcomes in family caregivers of people with a diagnosis of schizophrenia.

Methods

Study design: This quantitative study used a cross-sectional research design to collect data from respondents based on survey methodology. The study was descriptive in nature and involved a comparative analysis of caregivers of PWS (study group-SG) with a similar group of caregivers drawn from the General Medicine department (reference group-RG) of the hospital where data were collected. The RG was enlisted to provide a comparative basis in terms of our key variables. A correlational design was primarily used to identify significant correlates of QOL.

Setting for the study: The Thanjavur Medical College Hospital was established in 1964 and is a multi-speciality postgraduate institution attached to the Thanjavur Medical College in Tamilnadu, India. The hospital is run by the Government and draws its clientele mostly from the adjoining rural districts and provides high quality subsidised medical services and facilities.

Measures

Proactive Coping Inventory: (Greenglass, Schwarzer, Jakubiec, Fiksenbaum & Taubert (1999). The Proactive Coping Inventory is an inventory to assess skills in coping with distress, as well as those that promote greater well-being and greater satisfaction with life. The instrument has 55 items and measures 7 dimensions of coping namely, Proactive Coping; Reflective Coping; Strategic Planning; Preventive Coping; Instrumental Support Seeking; Emotional Support Seeking and Avoidance Coping. Responses are indicated on a four-point Likert scale with responses ranging from 'not at all true' to 'completely true'.

The Multidimensional Scale of Perceived Social Support: (Zimet, Dahlem, Zimet, & Farley (1988). This is a 12 item self-report measure of subjectively assessed social support. Three subscales, each addressing a different source of support, were identified and found to have strong factorial validity by the authors namely, Family, Friends, and Significant Other. Responses are scored on a 7-point Likert scale ranging from 'strongly agree' to 'strongly disagree'.

Schizophrenia Caregiver Quality of Life Questionnaire: (SCGQoL-Richier et al., 2011). This is a self-administered, multidimensional QoL instrument based on the point of view of caregivers of individuals with schizophrenia. It has 25 items and assesses QoL on seven dimensions namely, Psychological and Physical Well-being; Psychological Burden and Daily Life; Relationships with Spouse; Relationships with Psychiatric Team; Relationships with Family; Relationships with Friends and Material Burden. Each dimension and the total index score range from 0, indicating the lowest QoL, to 100, the highest QoL.

Data collection: Study Group (SG): Respondents were identified from among the caregivers of PWS who approached the Department of Psychiatry of the hospital

between July and December 2019. PWS received a diagnosis according to ICD 10 (International Statistical Classification of Diseases and Related Health Problems), F20 criteria (diagnostic criteria for schizophrenic disorders). Only caregivers who were living with and providing care to the PWS for at least six months at the point of data collection were included for the study. Further, caregivers themselves should not have received any psychiatric diagnosis. Eighty-two caregivers met these criteria and were approached for participation in the study, however only seventy-five of them provided consent for inclusion. The respondents were identified on a consecutive basis as they approached the hospital during the six-month period of data collection.

Reference group (RG): An equal number of caregivers (75) were identified during the same six-month period from the General Medicine Department of the same institution. The reference group respondents were enlisted to enable statistical comparison on the attributes being studied. These respondents were seeking treatment for a range of general health conditions such as fever, diarrhoea, body pain, vomiting etc. The same two inclusion criteria used for the selection of RG respondents were applied to this group as well. Data were collected from both groups by the second author after explaining the purpose of the study and soliciting voluntary participation of the caregivers.

Ethical considerations: The study received ethical clearance from the 'Institutional Ethical Committee' of Thanjavur Medical College (Ref: 192/2018). We received signed informed consent forms from all caregivers after explaining the nature of the study. They were told that they could drop out of the study at any point and their decision to participate or not would in no way influence the services being received from the institution. No personal identifying data was collected to maintain confidentiality.

Statistical analyses

Statistical Analysis: SPSS version 23 was used for data analysis. Student t tests were used for between group comparisons relating to the key variables. Pearson's correlation coefficients were computed to establish the statistical relationship among variables. Multiple regression analysis was used to

identify variables that predict the manifestation of QOL.

Results

Respondents' profile

Key background information pertaining to respondents of both groups is depicted in table 1. Comparisons based on the care recipients' age using t tests, did not indicate any statistically significant difference between both groups. Similarly, no significant differences were seen based on the age of the caregivers of both groups as well as their monthly income. Chi square tests were performed for qualitative variables such as care recipients' gender, their religion and marital status, revealing no statistical difference on these characteristics. Caregivers' gender and caregiving status (parent/spouse) also did not reveal any significant difference between both groups. All caregivers were married and predominantly were residents of adjoining rural areas. Thus, both respondent groups were matched on important socio-demographic attributes, and this ensured their comparability for this study. The key difference between both groups was the caregiving experience related to both patient groups.

Comparisons of both groups on key variables

Student t tests were used to compare both respondent groups on the key variables of the study and these results are presented in table 2. Significant statistical differences were obtained on all the variables of the study except for the 'relationship with friends' component of the SCGQoL. Comparisons based on mean scores for both groups revealed that caregivers of SG respondents were considerably lower than for the RG indicating poorer coping skills, lesser social support and poorer quality of life across all sub-dimensions that were assessed (Figure 1).

Comparisons based on demographic factors (SG only)

The first comparison was based on the age of the care recipient, and they were divided into two groups based on their mean age (35 years). t tests were then used to compare the two groups of caregivers based on the mean age (<35 years, n=49 and >36 years, n=26) on

all the variables. None of these comparisons were statistically significant.

The caregivers were then compared based on their own mean age (46 years) and t tests did not yield any statistically significant difference between the two groups (< 46 years, n=30 and >47 years, n=45) on any of the key variables of the study.

The next comparison was based on the caregivers' gender (Male=28; Female=47). t tests revealed statistically significant differences for the total SCGQOL score (t=2.72; df=73; p< .01). Mean scores when compared were higher for female caregivers (Mean=73.4) than for males (Mean=69). In terms of the sub-dimensions of QOL, significant differences were obtained for 'relationship with friends' (t=2.12; df=73; p< .05), 'relationship with spouse' (t=2.27; df=73; p< .05) and 'psychological burden and daily life' (t=2.82; df=73; p< .01) scores.

Comparisons based on the marital status of the care recipient in terms of whether they were single (n=39) or married (n=36), did not yield any statistically significant difference for any of the key variables.

The final comparison was based on the relationship to the care recipient; parent (n=39) or spouse (n=36). No statistically significant difference was obtained for any of the variables.

Correlations among variables (SG only)

No significant correlations were obtained for the total scores of all three variables (Table 3). Further, as expected sub-dimensions of the same scale obtained high correlations among themselves as well as with the total score of that dimension.

Significant negative correlations were obtained between proactive coping and psychological and physical well-being. Reflective coping also correlated negatively with psychological and physical well-being besides psychological burden and daily life scores. Preventive coping scores correlated negatively with all three sub-dimensions of social support relating to family, friends and significant other. Avoidance coping scores correlated negatively with psychological and physical well-being as well as psychological burden and daily life and material burden. Instrumental support, emotional support and

strategic planning all correlated positively with relationship with the spouse as well as with the psychiatric team.

The total QOL score entered into negative correlations with both reflective and avoidance coping, while avoidance coping, and material burden showed a significant negative relationship between themselves. Further, the family support dimension of the social support scale correlated positively with the family relationship sub-dimension of SCGQoL.

Predictors of QOL

We performed a regression analysis to identify the extent to which social support and coping influenced the manifestation of QOL. Standardised z scores were used in this analysis.

In the first step, coping and social support were included in the regression model as independent variables and the Total QOL score as dependent.

The resultant model was not significant ($R^2 = .07$, $F_{(2, 61)} = .07$, $p > .05$). Next an interaction term between social support and coping was created by multiplying their scores and this interaction term was added to the regression model. This model was significant, $R^2 = .18$, $F_{(3, 60)} = 5.33$, $p < .01$. The interaction term accounted for a significant proportion of the variance in Total QOL, $\Delta R^2 = .34$, $\Delta F_{(3, 60)} = 6.90$, $p < .05$, $\beta = -1.15$, $t_{(60)} = -2.62$, $p < .05$. However, neither coping nor social support by themselves were extracted as significant predictors of QOL in this model (Figure 2).

Table 1 Distribution of caregivers of both groups based on sociodemographic factors

| Details | SG (n = 75) | RG (n = 75) | Statistical test |
|------------------------|----------------|----------------|------------------|
| Care recipients | | | |
| Age (Range) | 19 to 60 years | 18 to 60 years | t= .05 |
| | Mean = 34.91 | Mean = 34.99 | p > .05 |
| Gender | | | |
| Male | 46 (61.3) | 44 (58.7) | $\chi^2 = .11$ |
| Female | 29 (38.7) | 31 (41.3) | p > .05 |
| Marital status | | | |
| Single | 39 (52.0) | 31 (41.3) | $\chi^2 = 1.71$ |
| Married | 36 (48.0) | 44 (58.7) | p > .05 |
| Duration of illness | 1 to 15 years | | |
| | Mean = 4.13 | | |
| Caregivers | | | |
| Age (Range) | 25 to 60 years | 25 to 60 years | t= 1.62 |
| | Mean = 46.24 | Mean = 44.15 | p > .05 |
| Gender | | | |
| Male | 28 (37.3) | 39 (52.0) | $\chi^2 = 3.26$ |
| Female | 47 (62.7) | 36 (48.0) | p > .05 |
| Marital status | | | |
| Single | 0 | 0 | |
| Married | 75 (100) | 75 (100) | |
| Relationship | | | |
| Husband | 15 (20.0) | 24 (32.0) | |
| Wife | 21 (28.0) | 26 (34.7) | $\chi^2 = 2.17$ |
| Father | 13 (17.3) | 15 (20.0) | p > .05 |

| | | | | |
|-----------------|--------------|-----------|--------------|----------------|
| Religion | Mother | 26 (34.7) | 10 (13.3) | |
| | Hindu | 68 (90.7) | 65 (86.7) | $\chi^2= 3.01$ |
| | Others | 7 (9.3) | 10 (13.3) | $p > .05$ |
| Occupation | Housewife | 44 (58.7) | 36 (48.0) | |
| | Farmer | 26 (34.7) | 39 (52.0) | |
| | Other | 5 (6.6) | - | |
| Income (Rupees) | 0 to 6000 | | 0 to 5000 | $-.05$ |
| | Mean =1633.3 | | Mean =2026.6 | $p > .05$ |
| Residence | Rural | 70 (93.3) | 70 (93.3) | |
| | Urban | 5 (6.7) | 5 (6.7) | |

Table 2 *t* test comparison of both groups on key variables

| Variable | *Group | Mean | **t Value |
|-------------------------------------|--------|--------|-----------|
| Proactive Coping | SG | 38.22 | 38.06 |
| | RG | 52.01 | |
| Reflective Coping | SG | 29.65 | 9.37 |
| | RG | 37.16 | |
| Strategic Planning | SG | 11.98 | 5.95 |
| | RG | 13.28 | |
| Preventive Coping | SG | 24.45 | 16.41 |
| | RG | 32.89 | |
| Instrumental Support Seeking | SG | 23.90 | 5.97 |
| | RG | 26.56 | |
| Emotional Support Seeking | SG | 14.93 | 6.90 |
| | RG | 17.13 | |
| Avoidance Coping | SG | 6.76 | 8.98 |
| | RG | 8.04 | |
| Total Coping Score | SG | 149.92 | 19.47 |
| | RG | 187.08 | |
| Family | SG | 24.14 | 13.45 |
| | RG | 28.00 | |
| Friends | SG | 23.89 | 12.46 |
| | RG | 26.86 | |
| Significant Other | SG | 24.04 | 5.86 |
| | RG | 25.00 | |
| Total Social Support Score | SG | 72.08 | 12.55 |
| | RG | 79.86 | |
| Psychological & Physical Well-Being | SG | 5.57 | 3.39 |
| | RG | 6.29 | |
| Psychological Burden and Daily Life | SG | 15.34 | 5.03 |
| | RG | 17.12 | |
| Relationship with Spouse | SG | 13.97 | 7.29 |

| | | | |
|------------------------------------|----|-------|-------|
| Relationship with Psychiatric Team | RG | 15.00 | |
| | SG | 14.22 | 7.95 |
| Relationship with Family | RG | 15.90 | |
| | SG | 9.44 | 8.43 |
| Relationship with Friends | RG | 10.00 | |
| | SG | 9.97 | .51** |
| Material Burden | RG | 10.04 | |
| | SG | 3.17 | 3.34 |
| Total SCGQOL Score | RG | 3.44 | |
| | SG | 71.77 | 6.81 |
| | RG | 77.84 | |

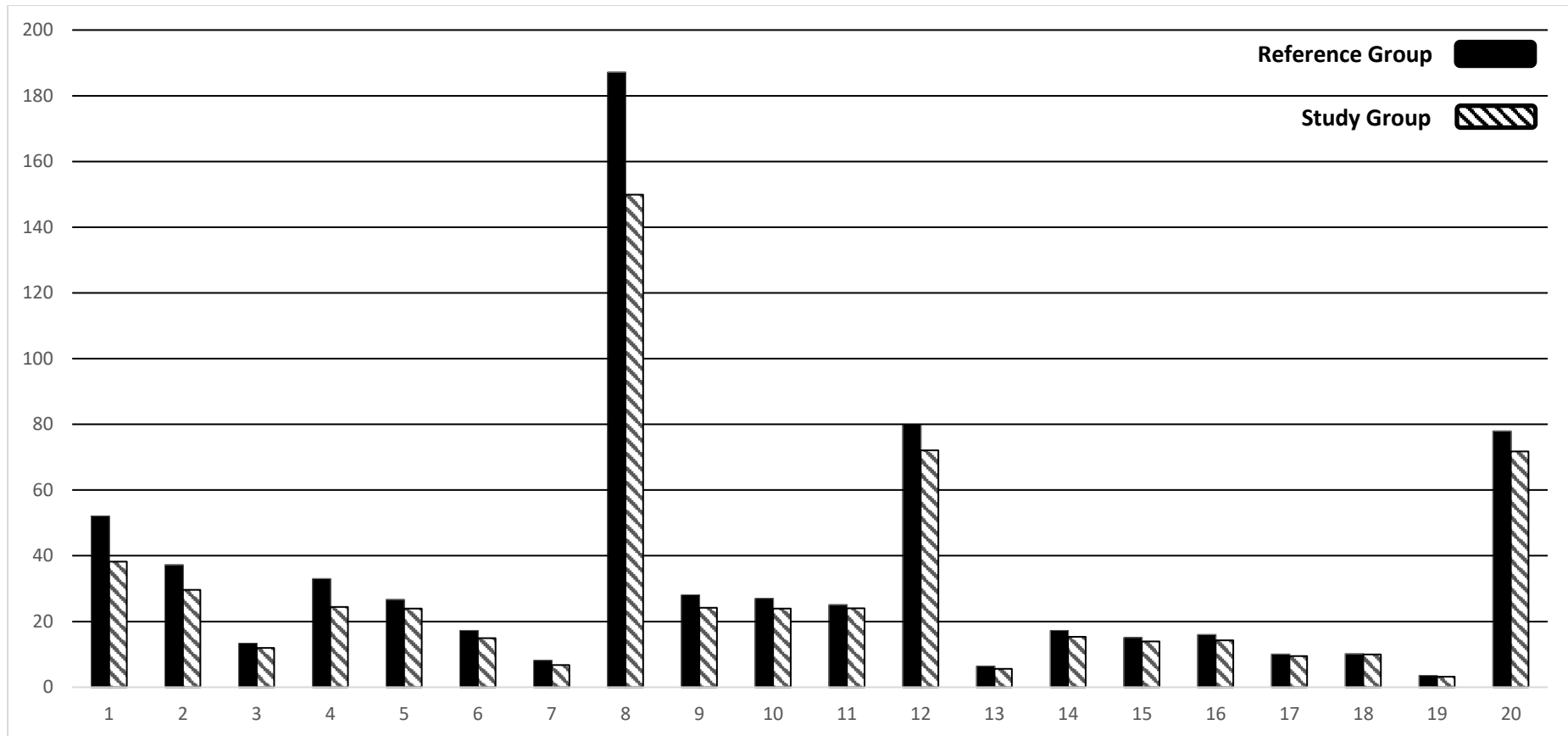
*n= 75; df= 148; **p > .05; p < .001 for all other variables

Table 3 Intercorrelation matrix for subject dimensions (SG only)

| Variable | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 | 13 | 14 | 15 | 16 | 17 | 18 | 19 | 20 |
|----------|-------|-------|--------|--------|--------|-------|--------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|----|
| 1 | 1 | | | | | | | | | | | | | | | | | | | |
| 2 | .83** | 1 | | | | | | | | | | | | | | | | | | |
| 3 | .28* | .11 | 1 | | | | | | | | | | | | | | | | | |
| 4 | .55** | .47** | .21 | 1 | | | | | | | | | | | | | | | | |
| 5 | .28* | .11 | 1.00** | .21 | 1 | | | | | | | | | | | | | | | |
| 6 | .28* | .11 | 1.00** | .21 | 1.00** | 1 | | | | | | | | | | | | | | |
| 7 | .93** | .82** | .06 | .65** | .06 | .06 | 1 | | | | | | | | | | | | | |
| 8 | .86** | .93** | .42** | .27* | .42** | .42** | .75** | 1 | | | | | | | | | | | | |
| 9 | .10 | .15 | -.18 | -.33** | -.18 | -.18 | .17 | .03 | 1 | | | | | | | | | | | |
| 10 | .14 | .25* | -.14 | -.31** | -.14 | -.14 | .20 | .14 | .87** | 1 | | | | | | | | | | |
| 11 | .18 | .12 | -.07 | -.28* | -.07 | -.07 | .21 | .07 | .83** | .69** | 1 | | | | | | | | | |
| 12 | .14 | .18 | -.15 | -.33** | -.15 | -.15 | .21 | .08 | .98** | .92** | .88** | 1 | | | | | | | | |
| 13 | -.28* | -.25* | .04 | .12 | .04 | .04 | -.31** | -.23* | -.18 | -.13 | -.14 | -.17 | 1 | | | | | | | |
| 14 | -.22 | -.28* | .22 | .13 | .22 | .22 | -.31** | -.21 | -.20 | -.19 | -.18 | -.20 | .82** | 1 | | | | | | |
| 15 | -.03 | -.19 | .28* | .12 | .28* | .28* | -.14 | -.07 | -.12 | -.14 | -.11 | -.13 | .36** | .71** | 1 | | | | | |
| 16 | -.01 | -.14 | .24* | .14 | .24* | .24* | -.10 | -.03 | .13 | .09 | -.10 | -.12 | .45** | .64** | .90** | 1 | | | | |
| 17 | .01 | -.21 | -.11 | -.01 | -.11 | -.11 | .05 | -.19 | .24* | .26* | -.15 | -.24* | .41** | .49** | .42** | .50** | 1 | | | |
| 18 | .06 | -.09 | .21 | .04 | .21 | .21 | -.01 | -.01 | .13 | .16 | -.19 | -.16 | .01 | .48** | .66** | .51** | .46** | 1 | | |
| 19 | -.21 | -.13 | .05 | .16 | .05 | .05 | -.23* | -.11 | -.21 | .11 | -.21 | -.19 | .87** | .67** | .38** | .60** | .44** | .01 | 1 | |
| 20 | -.14 | -.26* | .22 | .14 | .22 | .22 | -.23* | -.16 | -.21 | .20 | -.19 | -.22 | .75** | .94** | .83** | .83** | .62** | .58** | .71** | 1 |

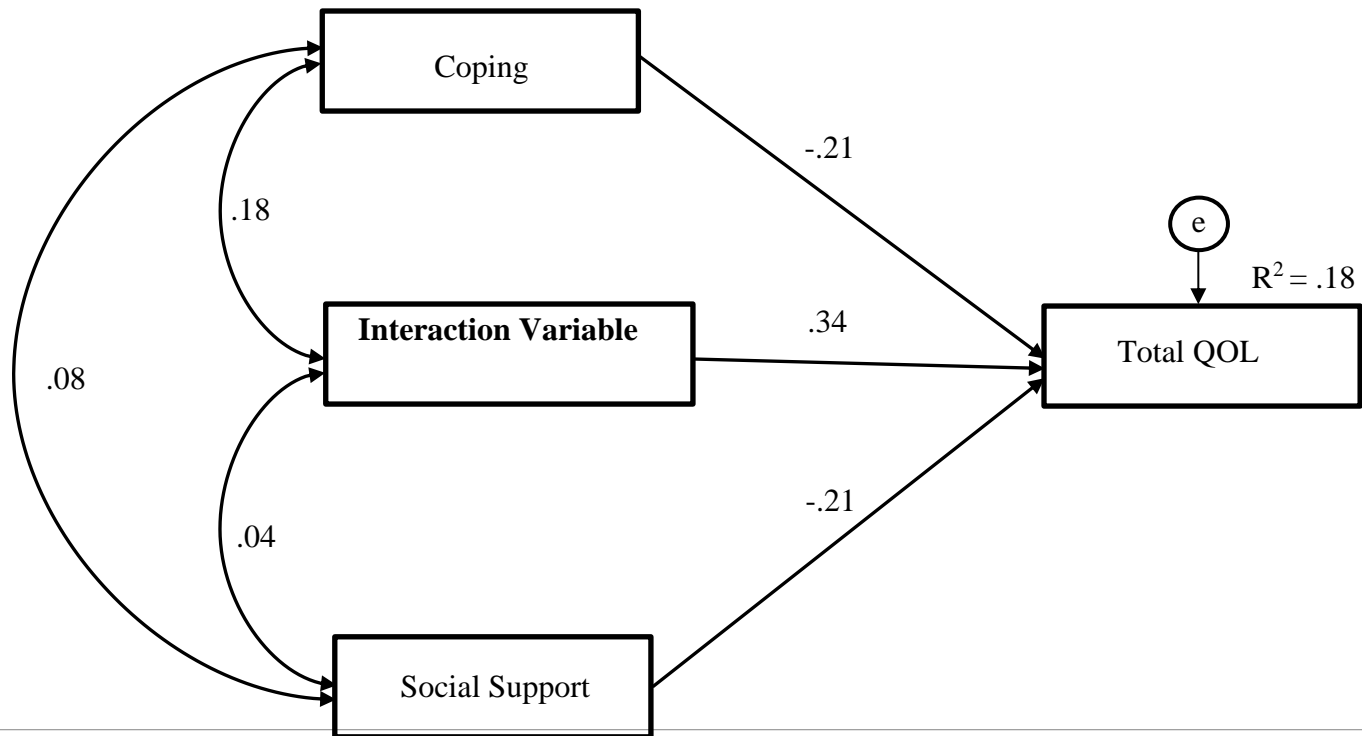
Variable key: 1-Proactive Coping; 2-Reflective Coping; 3-Strategic Planning; 4-Preventive Coping; 5-Instrumental Support Seeking; 6-Emotional Support Seeking; 7-Avoidance Coping; 8-Total Coping Score; 9-Family support; 10-Friends support; 11-Significant Other support; 12-Total Social Support score; 13-Psychological and Physical Well-Being; 14-Psychological Burden and Daily Life; 15-Relationship with Spouse; 16-Relationship with Psychiatric Team; 17-Relationship with Family; 18-Relationship with Friends; 19-Material Burden; 20-Total SCGQOL score

Figure 1 Bar chart depicting both groups on mean scores of key variables



1-Proactive Coping; 2-Reflective Coping; 3-Strategic Planning; 4-Preventive Coping; 5-Instrumental Support Seeking; 6-Emotional Support Seeking; 7-Avoidance Coping; 8-Total Coping Score; 9-Family; 10-Friends; 11-Significant Other; 12-Total Social Support; 13-Psychological and Physical Well-Being; 14-Psychological Burden and Daily Life; 15-Relationship with Spouse; 16-Relationship with Psychiatric Team; 17-Relationship with Family; 18-Relationship with Friends; 19-Material Burden; 20-Total SCGQOL score

Figure 2 Interaction analysis for Total QOL



Discussion

Results indicate that the typical profile of the caregiver in this study corresponds to a middle-aged wife or mother who provides care for an unmarried male recipient who has a diagnosis of schizophrenia, and this conforms with the profile of caregivers and their recipients typically seen in the literature (e.g., Boyer et al., 2012). On comparing parents and spousal caregivers in terms of their quality of life, coping strategies and perceived social support, no statistically significant differences were observed. Further, t tests did not generate any significant difference in relation to the key variables of the study in terms of either the age of the caregiver nor that of the care recipient. This suggests that caregiving roles, responsibilities, and associated hardships are a uniform experience across age groups and that it did not really matter how young or old the caregiver or recipient was. However, some other studies (e.g., Ribe et al., 2018) have reported an association between caregivers' QOL and their age. A notable finding was in terms of the gender of the caregivers, and we found that female caregivers had better QOL than their male counterparts and the sub-dimension scores reveal that this was due to their relationship with their spouse and with friends, thus indicating better social support available to them. This finding however does not agree with that of Winahyu et al., (2015) who did not find caregiver gender to be a significant variable in influencing perception of burden and QOL.

Our results clearly demonstrate that in comparison with the control group, caregivers of PWS experience lower social support, have lower coping scores, and manifest poorer QOL. This is in consonance with observations both in the western literature (e.g., Margetic et al., 2013; Ribe et al., 2018) as well as findings from India (e.g., Stanley et al., 2016; Grover et al., 2015). Factors such as symptom severity of care recipients (Maeng, 2016), higher perceived burden by caregivers (Rahmani et al., 2019) and role distress in caregivers (Quah, 2014) have been offered as possible explanations for reduced QOL among caregivers of PWS. Social support has also been identified as a key determinant in this regard (Chien & Lee, 2010). Stigma associated with the caregiving of mentally ill

persons could be a possible reason for perceived lack of social support for young female caregivers in the Indian context (Singh, Mattoo & Grover, 2016).

While the current study shows lesser perceived social support by caregivers, an earlier Indian study suggests that the majority of the relatives failed to maintain social contacts (Chandrasekaran, Sivaprakash & Jayestri, 2002). The literature holds that poor social support is related to more frequent use of emotion-focused strategies, whereas use of problem focused coping strategies was associated with the availability of higher levels of practical and emotional social support and of professional help (Magliano et al., 1998). However, we have not elicited a statistical relationship between coping and social support in this study.

Our key finding however is that it is neither social support by itself nor the overall coping efforts of the caregivers, but the interaction between the two that ultimately determines QOL. It is hence important that psychotherapeutic efforts are directed in a two-pronged effort to simultaneously enhance coping strategies as well as to ensure the provision of adequate social support mechanisms for caregivers.

Implications for intervention

We agree with the notion that family caregivers need to be provided with unrelenting support to enable them to re-focus and learn to manage illness-related roles and tasks (Bhatia & Gupta, 2003). Family psychoeducation programmes have demonstrated significant improvement in overall quality of life scores for family caregivers. Furthermore, it has been demonstrated that family psychoeducation has been effective in reducing caregiver burden (Sharif, Shaygan & Mani, 2012; Thimmajja & Rathinasamy, 2019) and this is significant given the inverse relationship between caregiver burden and their quality of life (Tristiana, Triantoro, Nihayati, Yusuf, & Khatijah, 2019; Ribe et al., 2018). Psychoeducational family intervention, and family therapy have also been shown to improve caregiver coping skills and reduce the impact of caregiving (Bauml, Frobose, Kraemer, Rentrop & Pitschel-Walz, 2006). Imparting factual

information about symptoms and clinical manifestations of schizophrenia, home management of patients, especially in relation to high expressed emotion and possibility of relapse, identifying early sign and symptoms of illness and the importance of regular medications of the patients have been suggested in this regard (Verma, Walia, Chaudhury & Srivastava, 2019). Psychoeducation programmes need to focus on empathic engagement, providing ongoing support and better access to clinical resources besides enhancement of social networks and improving coping strategies (Stanley & Shwetha, 2006). Peer support that involves sharing and learning from the experiences of other caregivers are a useful option that could also provide comfort in the knowledge

that one is not alone in facing distressful situations (Stanley, Balakrishnan & Ilangovan, 2017b). Family to family education programmes have successfully demonstrated their effectiveness in terms of providing necessary social support for family caregivers in terms of enhancing their mental status and improving their coping (Bademil & Duman, 2014; Dixon et al., 2011). They have also been found beneficial for the management of difficult behaviours in youth with mental health difficulties (Schiffman et al., 2015). Such initiatives provide practical guidance in management of illness related issues besides providing an opportunity for sharing of feelings and emotions related to caregiving. It is important for the clinical team to adopt a participatory approach and to maintain a working alliance with the caregivers (Ran et al., 2016) and to train and provide support to them in order to enable their engagement in the recovery process (Tsui & Tsang, 2017). Unfortunately, family caregivers in the Indian context do not merit the recognition that they rightly deserve as being crucial players in the management of the person with schizophrenia.

Limitations of the study

The cross-sectional nature of the study does not capture the dynamics of the caregiver-recipient relationship as it changes over time. This could in turn influence the QOL and nature of coping seen in the caregivers.

The scope for generalisation of the findings from this study are limited and may not be

appropriately extended to other countries, communities, and settings. Further, as data was collected in a clinical setting, our findings may not be generalised for people in community-based rehabilitation programmes where caregivers may receive other and different forms of social support that may influence their overall QOL.

While our study reveals that coping strategies used by caregivers of PWS were lesser than those used by the comparative group, the data does not indicate which types of coping strategies were predominantly used by both groups. Similarly, while poor social support from family, friends and significant others have been elicited in this study, the reasons for the same have not been identified.

Despite these limitations, this study adds to the literature on caregiving in schizophrenia in India. It has identified the interactional role played by social support in conjunction with coping efforts in influencing QOL in family caregivers. Further, the use of a reference group has added to the empirical robustness of our study as it provides a basis of comparison with families not caring for a person with acute mental illness.

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