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Family Caregiving in Schizophrenia: do stress, social support and resilience influence life satisfaction? - A quantitative study from India

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ABSTRACT

Family caregivers play a crucial role in providing care and support for people with mental health conditions, such as schizophrenia. A quantitative design was used to assess caregivers of people with a diagnosis of schizophrenia (PWS) in relation to their stress levels, perceived social support, resilience, and life satisfaction. Standardized instruments to assess the manifestation of the key variables were administered to 75 caregivers identified within a clinical setting in south India using survey methodology. Regression analyses reveal that while resilience mediates the influence of stress on life satisfaction, social support did not moderate the effect of stress on resilience.

KEYWORDS

Family caregiving;
Caregiving In Schizophrenia;
Caregiver Resilience;
Caregiver Stress; Caregiver
Perceived Social support;
Caregiver Life Satisfaction

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, 2022). Family members play a key role in providing care and support for relatives who are suffering from mental illness. This is particularly true of Asian communities where cultural norms place the onus of providing care on the next of kin of the ill person. Sociocultural expectations view the caregiving function as typically being discharged by either parents, children, or the spouse and as a family obligation that has morally binding undertones (Stanley, Mettilda, & Bhakyalakshmi, 2016). Family caregivers in India consider their role as being an integral part of their lives, routed in the Hindu belief of “dharma” (mandatory social responsibilities toward others) (Banerjee & Dixit, 2012). Caregivers of people with schizophrenia and experience significant stress levels and psychosocial burden (Wan & Wong, 2019). They often experience grief and have to cope with stigma and social isolation, which leaves them with feelings of shame, embarrassment, or guilt (Kulhara, 2012).

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Studies from India have also reported high levels of caregiver burden in family members who look after a relative diagnosed with schizophrenia (e.g., Arun, Inbakamal, Tharyan, & Premkumar, 2018; Kuchhal et al., 2019). The volatile nature of the disorder and its accompanying debilitating consequences pose a considerable burden on family caregivers owing to its physical, social, emotional, and financial implications (Stanley, Balakrishnan, & Ilangovan, 2017). Caregivers experience considerable burden in relation to finances, family relationships, as well as their own well-being and health (Gupta, Isherwood, Jones, & Van Impe, 2015; Kumar, Suresha, Thirthalli, Arunachala, & Gangadhar, 2015). While caregiver stress and burden are not synonymous, they tend to mutually reinforce one another. Research has consistently documented that the pernicious consequences of stress for caregivers indicates that they may be at increased risk for deteriorated psychological well-being (Pearlin & Bierman, 2013).

Added to this is the issue of stigma associated with mental illness that impacts the immediate family of the person with schizophrenia. It has been noted that caregiver stigma is associated with higher levels of positive symptoms of schizophrenia, higher levels of disability, and younger age of the PWS (Koschorke, Padmavati, Kumar, Cohen, & Weiss et al., 2017). While it has been widely documented that the experience of stigma results in discrimination and social exclusion, it has been suggested that perceived social support mediates the relationship between the impact of experienced discrimination and mental health (Kondrat, Sullivan, Wilkins, Barrett, & Beerbower, 2018).

Social support refers to the resources available to an individual, which are provided by members of their social networks, including friends, family members, acquaintances, and health-care professionals (Nausheen, Gidron, Peveler, & Moss-Morris, 2009). Caregivers may feel isolated from friends and family owing to the time and effort spent in care provision (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014). Several previous studies have identified reduced social support available to these families (Chen, Zhao, & Tang et al., 2019; Magliano, Fiorillo, Malangone, De Rosa, & Maj, 2006). It is important to note that a significant positive correlation has been reported between social support and quality of life in PWS (Prabhakaran, Nagarajan, Varadharajan, & Menon, 2021).

Resilience is an important concept often mentioned in the context of stress coping and a high positive correlation between resilience and perceived social support has been established in recent research (Lök & Bademli, 2021). The transactional model of stress posits that resilience as a moderator, can attenuate the adverse impact of stress on psychosocial functioning (Ifeagwazi, Chukwuorji, & Zacchaeus, 2015). It has been reported that lower levels of resilience among caregivers of people with mental illnesses contribute to greater psychological distress and that resilience moderates the relationship between stigma and psychological distress in family caregivers of PWS (Chen

et al., 2016). Resilience, and social support also mediate between caregiving burden and positive aspects of caregiving (Wang, Bai, Lou, Pang, & Tang, 2020) and there is significant positive correlation between resilience levels and quality of life (Abd El-Ghafar, Abd El-Nabi, & Fathalla, 2018).

Life satisfaction is the cognitive component of subjective well-being and refers to the global evaluation of the quality of one's life as a whole (Pavot & Diener, 1993). Caregiver life satisfaction is seen to be inversely related to caregiver and care recipient rated symptom severity with each influencing the other (Athay, 2012). Caregivers have lower life satisfaction and higher depression scores relative to a population of non-caregivers (Lee, Bierman, Penning, & Kemp, 2020). It has also been evidenced by Lakhani and Sakatkar (2016) that caregiver life satisfaction correlates negatively with the burden of care and also with self-efficacy in caregiving.

The theoretical model

The stress process model (Pearlin, Lieberman, Menaghan, & Mullan, 1981) suggests that caregiving is a stressor by itself that can result in psychological distress. Kinship, social support, coping, and culture are some of the contextual factors that determine the impact of caregiving stress (Pearlin, Mullan, Semple, & Skaff, 1990). The model considers four domains that are implicated in the process of experiencing stress: (1) the context and background in which stress is experienced that is influenced by the characteristics of the caregiver; (2) primary stressors such as behavioral problems and extent of dependency of the care recipient and resulting secondary stressors, such as family conflict, and impact on self-esteem; (3) mediators of stress such as coping responses and the availability of social support and (4) outcomes or manifestations of stress that influence the physical and mental well-being of the caregiver (Ajay, Kasthuri, Kiran, & Malhotra, 2017; Pearlin et al., 1990).

Based on this framework our conceptual model for this study is diagrammatically presented in [Figure 1](#). We propose that stress the independent variable would have both a direct influence on the experience of life satisfaction, the dependent variable, and also an indirect pathway via resilience that mediates the influence of stress on life satisfaction. We further propose that the pathway of influence from stress to resilience is moderated by the extent of social support perceived by the caregivers.

An understanding of these variables and the relationship among them would facilitate the introduction of appropriate strategies that could potentially enhance the caregiving experience and result in better life satisfaction for family caregivers. This study was planned against this background and seeks to

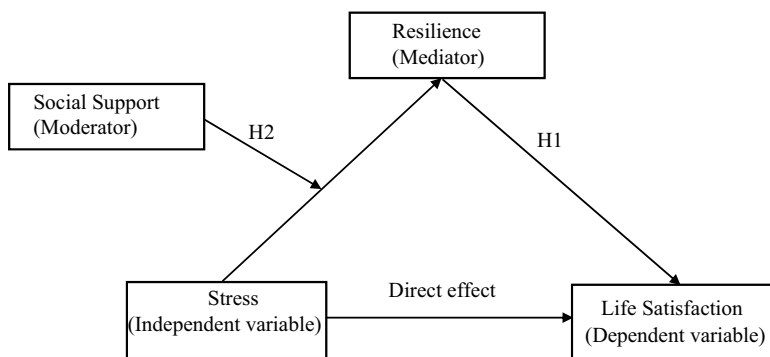


Figure 1. Depicting the conceptual framework of the study.

examine the role played by stress, resilience, and perceived social support in influencing the life satisfaction in family caregivers of people with a diagnosis of schizophrenia (PWS). We hypothesized that:

H1: Resilience would mediate the influence of stress on life satisfaction.

H2: Social support would moderate the pathway between stress and resilience.

Method

Study design

The study used a cross-sectional design as data was collected at a single point of time. The analytic design is predominantly correlational, and a nonrandom consecutive sampling procedure was used to recruit respondents. Data was collected using survey methodology.

Setting for the study

The Thanjavur Medical College Hospital established in 1964, is a multi-specialty postgraduate educational institution cum hospital in Tamilnadu, India. The hospital is run by the Government and draws its clientele mostly from the adjoining rural districts and provides high-quality subsidized medical services and facilities. The respondents for this study were drawn from the department of Psychiatry of this institution where they were receiving services for a family member with a diagnosis of schizophrenia. The hospital provides both outpatient and in-patient services besides providing psychological testing and different forms of psychotherapies. Social work services both individual and group work activities are provided to the in-patients.

Instruments

Self-prepared socio-demographic questionnaire to collect basic background data regarding the caregivers and the PWS.

The Perceived Stress Scale (Cohen, Kamarck, & Mermelstein, 1983) is a widely used psychological instrument for measuring the perception of stress. It is a measure of the degree to which situations in one's life are appraised as stressful. The 10-item measure was designed to assess how unpredictable, uncontrollable, and overloaded respondents find their lives and responses are provided on a five-point Likert scale. The Cronbach's alpha of this measure in the present study was .82 which indicates "good" reliability (George & Mallery, 2003).

Brief Resilience Scale by Smith et al. (2008) provides a composite measure of self-reported resilience. It is a six-item instrument with items rated on a 5-point Likert scale with responses ranging from strongly agree to strongly disagree. High scores indicate higher resilience. The Cronbach's alpha in the present study was .74 which indicates an "acceptable" extent of reliability (George & Mallery, 2003).

The Satisfaction with Life Scale by Diener, Emmons, Larsen, and Griffin (1985) is a 5-item scale designed to measure global cognitive judgments of one's life satisfaction. Participants indicate how much they agree or disagree with each of the five items using a 7-point scale that ranges from 7-strongly agree to 1-strongly disagree. The alpha value computed in this study was .78 which is an "acceptable" indicator of scale reliability (George & Mallery, 2003).

The Multidimensional Scale of Perceived Social Support Zimet, Dahlem, Zimet, and 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."

Translation validity of instruments: In order to translate the instruments into the native vernacular (Tamil), the English versions were translated independently by two experts outside the research team. The two Tamil versions were then compared for consistency and a final single Tamil version generated following an item-wise discussion for each instrument and based on consensus between the experts. This consensus version was then back translated into English by a third person and the back translated English version then compared with the original English version. Minimal inconsistencies between the two English versions indicated that the Tamil version generated had reliable translation validity and could be used for data collection.

Data collection

Respondents were identified from among the caregivers of PWS who approached the Department of Psychiatry of the hospital. Seventy-five caregivers of patients who approached the department for treatment and were admitted as in-patients were included as respondents. They had received a diagnosis of schizophrenia from the consultant psychiatrist in accordance with ICD-10 criteria. Data were collected by the second author in person at the point of initial contact with the clinical team after explaining the purpose of the study and soliciting voluntary participation of the caregivers. The PWS at this point had not received any treatment and were symptomatic. Only caregivers who were living with the PWS at the time of data collection and who identified themselves as having significant responsibility for the PWS were included for data collection. Data were collected from the primary caregiver (spouse, mother, father, sibling) who were present with the PWS at the time of data collection.

Ethical considerations

The study received ethical clearance from the “Institutional Ethical Committee” of (*Anonymized Name of Institution*). We received signed informed consent forms from prospective 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. Participation was voluntary and no personal identifying data was collected in order to maintain confidentiality. No financial incentives were provided for participation in the study.

Statistical analyses

SPSS version 23 was used for statistical analysis. t tests were used for within group comparisons based on age, marital status, gender, and caregiver relationship. 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 life satisfaction in the respondents. We used the “process” macro (<https://processmacro.org/>) developed by Hayes (2018) to identify if resilience mediated the relationship between stress and life satisfaction and if social support was a moderator variable between the two. Model 7 as suggested by Hayes (2018) was used for this mediated moderation analysis. Amos software (v.23) was used to generate the path diagram to depict the moderated-mediation model.

Results

Respondents' sociodemographic profile

Key background information pertaining to the caregivers as well as the care recipients is depicted in Table 1. The caregivers were the respondents of the study. They were all married and the majority in both groups were housewives. They all belonged to the Hindu religion.

Caregiver profile on the key variables of the study is portrayed in Table 2. They have been categorized as being “low” or ‘high on each of the key variables based on the mean score. It is seen that the majority have been classified as being in the “low”

Table 1. Comparative profile of caregivers and PWS on sociodemographic factors

Care recipients (PWS)			
Age (Range)	19 to 60 years Mean = 34.91		
Gender	Male	46 (61.3)	
	Female	29 (38.7)	
Marital status	Single	39 (52.0)	
	Married	36 (48.0)	
Duration of illness	1 to 15 years Mean = 4.13		
<i>Caregivers</i>			
Duration of caregiving	1 to 15 years Mean = 4.13		
Age (Range)	25 to 60 years Mean = 46.24		
Gender	Male	28 (37.3)	
	Female	47 (62.7)	
Marital status	Single	0	
	Married	75 (100)	
Relationship	Spouse	36 (48.0)	
	Parent	39 (52.0)	
Religion	Hindu	68 (90.7)	
	Others	7 (9.3)	
Occupation	Housewife	44 (58.7)	
	Farmer	26 (34.7)	
	Other	5 (6.6)	
Income (Rupees per month)	0 to 6000 Mean =1633.3		
Residence	Rural	70 (93.3)	
	Urban	5 (6.7)	

^{Notes} *Note: Figures in parentheses are percentages*

Table 2. Profile of respondents on key variables.

Variable	Minimum	Maximum	Mean	SD	Low	High
Stress	8	10	8.84	0.99	43 (57.3)	32 (42.7)
Resilience	12	23	18.60	4.41	22 (29.3)	53 (70.7)
Life Satisfaction	23	27	24.76	1.32	55 (73.3)	20 (26.7)
Social Support	64	80	72.08	5.23	51 (68.0)	24 (32.0)

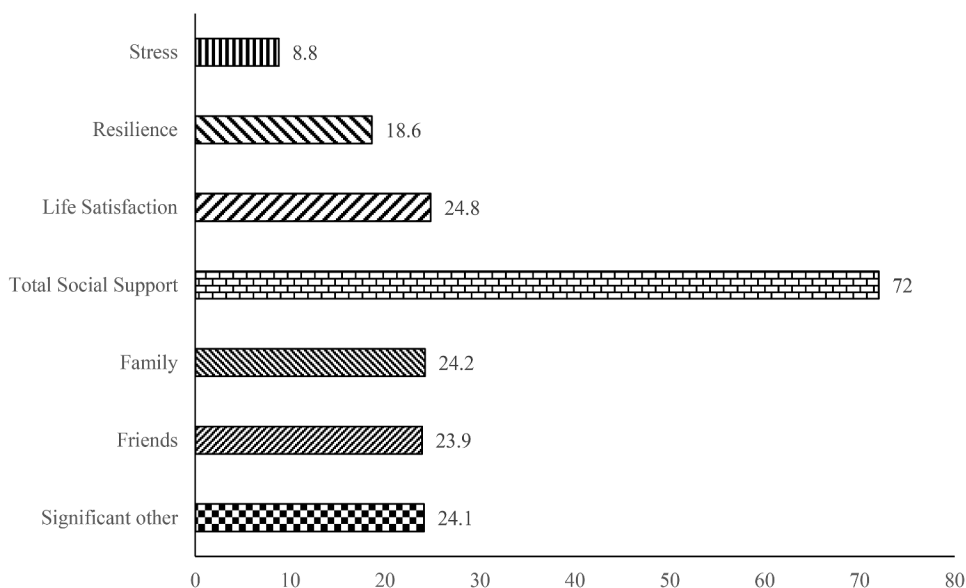


Figure 2. Bar Chart Depicting Mean Scores of Key Variables.

stress category but are in the high resilience group. The life satisfaction scores are low for the majority as well as being low in terms of perceived social support. The mean score profile of the respondents is graphically represented in [Figure 2](#).

Within group comparisons based on demographic factors

Based on the low and high categorization of respondents on the key variables, t tests were then executed to check for significant statistical differences between these two categories. However, no statistically significant differences were seen between the two groups based on the caregivers' and care recipients' age, the caregivers' income, the duration of caregiving or the average time spent on caring functions per day. Furthermore, no statistically significant differences were seen on all the key variables based on both caregivers' and recipients' gender. A statistically significant difference was seen only for the caregivers' stress scores based on the marital status of the care recipients (Single: $M = 9.08$, $SD = 1.01$; Married: $M = 8.58$, $SD = .91$; $t = 2.22$, $p < .05$) and their relationship with the recipient (Parent: $M = 9.08$, $SD = 1.01$; Spouse: $M = 8.58$, $SD = .91$; $t = 2.22$, $p < .05$).

Correlations among variables

Significant statistical positive correlations were obtained for stress, resilience, and life satisfaction scores. However, none of these variables correlate significantly with either the total social support score or any of its three components. As expected, the component scores of social support scale evidenced strong positive correlations between themselves and with the total support score.

Table 3. Inter-correlation matrix for key variables.

Variables	1	2	3	4	5	6	7
1.Stress	1						
2.Resilience	.31**	1					
3.Life Satisfaction	.61**	.45**	1				
4.Social Support	.09	.02	.08	1			
5.Family	.02	.08	.01	.98**	1		
6.Friends	.10	.02	.09	.92**	.87**	1	
7.Significant Other	.17	.05	.19	.89**	.84**	.69**	1

** Correlation is significant at the 0.01 level (2-tailed).

With regard to socio-demographic variables, such as age, income, duration of caregiving, these variables showed some correlations amongst themselves but not with any of the key variables of the study (Table 3).

Predictors of life satisfaction: mediators and moderators

A moderated mediation analysis was run to test the theoretical model advanced in figure 1 using the PROCESS macro for SPSS with the mean composite scores on the items for each construct (Hayes, 2018). These results are depicted in figure 3 and summarized in table 4. Social support was introduced as a moderator of the relationship between stress and resilience, and resilience placed as the mediator of the relationship between caregiver stress (independent variable) and life satisfaction (dependent variable). The analyses assessed (1) the effects of stress on life satisfaction (both directly and indirectly, through resilience), (2) the effect of stress on resilience (as moderated by social support), and (3) the effect of resilience on life satisfaction. The analysis combines mediation and moderation to estimate the conditional indirect effect of stress on life satisfaction through resilience as moderated by social support (Model 7 by Hayes, 2018; see Figure 3). The statistical significance of the direct and indirect effects was evaluated by means of 5,000 bootstrap samples to create bias-corrected confidence intervals (Cis: 95%) with heteroscedasticity-consistent SEs (Hayes, 2018).

The results indicate significant direct effects of stress on resilience (effect = 1.39, $p < .01$) as well as on life satisfaction (effect = .70, $p < .001$). The direct effect of resilience on life satisfaction was also significant (effect = .09, $p < .01$). These significant effects establish resilience as a mediating variable between stress and caregiver life satisfaction thus validating our first hypothesis (H1).

Results also indicate that both social support (effect = $-.04$, $p > .05$) and the interaction variable (social support X stress; effect = .09, $p > .05$) do not exert a statistically significant effect on resilience. Hypothesis H2 hence stands rejected.

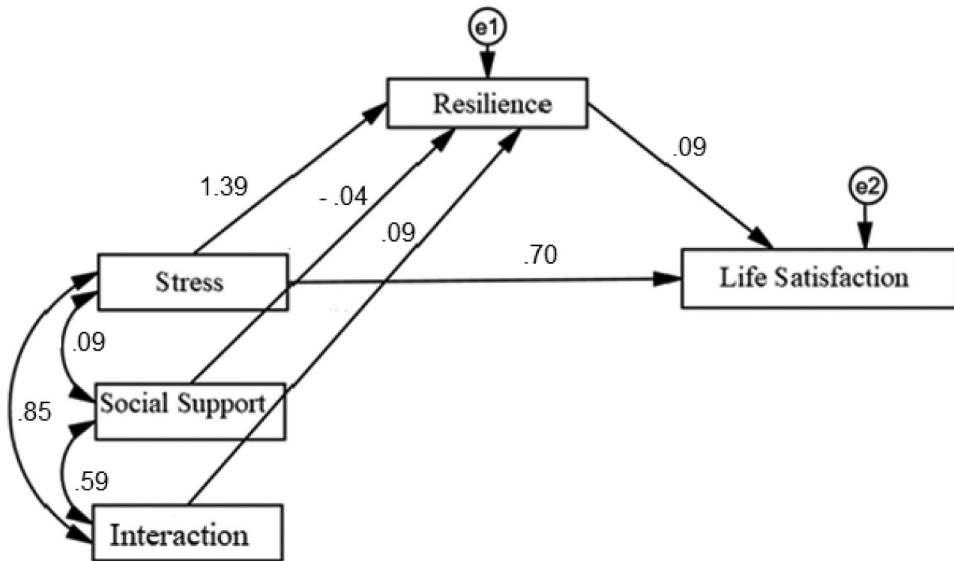


Figure 3. Path diagram depicting mediators and moderators of the relationship between Stress and Life Satisfaction.

Table 4. Summary Results of Moderated-Mediation Analysis.

Path	Coefficient	SE	t	p	LLCI	ULCI
Stress on Resilience	1.39	.50	2.78	.007	.39	2.40
Stress on Life satisfaction	.70	.12	5.67	.000	.46	.95
Social support on Resilience	-.04	.09	.42	.676	-.23	.15
Interaction variable on Resilience	.09	.09	1.04	.301	-.09	.29
Resilience on Life satisfaction	.09	.03	3.10	.003	.03	.14

LLCI = lower limit confidence interval; ULCI = upper limit confidence interval

Discussion

The profile of the typical caregiver in this study is that of a middle-aged mother caring for a single young male care recipient with a diagnosis of schizophrenia. This conforms to the caregiver and recipients typically seen in the caregiving literature on schizophrenia (e.g., Boyer et al., 2012). We found that parental caregivers had significantly higher stress scores than those caring for spouses, and this agrees with an earlier study done in India (Kuchhal et al., 2019). Stress scores were also significantly different for those caring for single care recipients than those married. Except for the stress scores, we did not find any difference between parents and spousal caregivers in terms of the other variables studied. Our results also show that the age of the caregiver or that of the recipient did not influence the caregiving experience in any way as indicated by our statistical analyses. This suggests that the 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 the recipient is. We also did not obtain any gender differentials for all our key variables. Earlier studies from India (Khan, Panday, & Kiran, 2017; Raj, Shiri, & Jangam, 2016) which assessed social support in male and female caregivers of PWS also report no gender-based difference.

The majority of the respondents have been classified as being in the “low” stress category though there are considerable numbers in the high-stress category as well. The literature from India and elsewhere also holds that caregivers of relatives with schizophrenia and early psychosis experience significant stress and psychosocial burden (e.g., Ebrahim, Al-Attar, & Gabra et al., 2020; Sadath, Muralidhar, Varambally, Gangadhar, & Jose, 2017; Stanley et al., 2017; Wan & Wong, 2019). It has been held that caregiving in general has all the features of a chronic stress experience as it creates physical and psychological strain over extended periods of time, is accompanied by high levels of unpredictability and uncontrollability, and has the capacity to create secondary stress in multiple life domains, such as work and family relationships (Schulz & Sherwood, 2008). It would appear that this stress is the predominant reason for the reduced feelings of life satisfaction that we have seen in this study and our findings agree with the caregiving literature on schizophrenia regarding lower levels of life satisfaction in caregivers of PWS compared to non-caregivers (M, 2005).

This study shows lesser perceived social support by caregivers of PWS. This is consistent with an earlier study by Sadath et al. (2017). Another Indian study suggests that the majority of the relatives failed to maintain social contacts (Chandrasekaran, Sivaprakash, & Jayestri, 2002). This could be owing to not being able to find the time or opportunity to meet friends and family owing to the pressure of caregiving. Another reason for reduced social support suggested by the literature is the stigma associated with the caregiving of mentally ill persons in the Indian context (Singh, Mattoo, & Grover, 2016). Network contraction and condensation have been associated with families having a PWS that could account for the diminished social support available to these families (Sawant & Jethwani, 2010).

An encouraging finding of our study is that the majority of the respondents’ manifest high resilience levels despite less social support and life satisfaction. This shows their ability to thrive in spite of adverse circumstances and would certainly enhance their ability to manage the contextual demands being experienced by them in relation to caregiving.

We have obtained significant statistical positive correlations for stress, resilience, and life satisfaction scores in this study. Thus, contrary to expectation, in spite of high stress levels, a high manifestation of life satisfaction is also seen. This could be explained by the literature relating to positive aspects of caregiving in schizophrenia (Stanley & Balakrishnan, 2021) which highlights that in spite of the stress associated with caregiving, caregivers also perceive certain positive rewards associated with the caregiving function. Some of these

caregiving gains pertain to enhanced affection, family solidarity and self-confidence to name a few (Shiraishi & Reilly, 2019). From the Hindu Indian perspective, satisfaction would also accrue from the discharge of one's *dharma* that refers to the notion of discharging social responsibilities toward others as mandated by Hindu religious beliefs (Banerjee & Dixit, 2012).

Our conceptual model in this study was only partially validated. In brief, our findings indicate that stress has both a direct effect on life satisfaction and an indirect pathway via the manifestation of resilience. Resilience thus is a crucial mediator of the influence of stress on life satisfaction. On the other hand, social support does not moderate the influence of stress on resilience. An earlier study from India (Stanley & Balakrishnan, 2021) found life satisfaction scores to be significant predictors of resilience of family caregivers of PWS. The current study shows a direct pathway from resilience to life satisfaction. Taken in conjunction with the previous study, it appears that both resilience and life satisfaction tend to mutually influence each other in a positive manner.

Implications for practice

Our results suggest that there are significant gains to be made in terms of strengthening resilience in caregivers of PWS for enabling better stress management and thereby enhancing their life satisfaction.

Caregiver-directed psychosocial interventions can complement psychiatric care and help them to better understand mental illness, improve coping skills, enhance adjustment, and also facilitate healthy support behaviors (Ashcroft, Kim, Elefant, Benson, & Carter, 2018). The literature suggests that family-oriented programs have benefits not only for the caregivers but also for the PWS. Meta-analyses conducted earlier (Okpokoro, Adams, & Sampson, 2014; Pharoah, Mari, Rathbone, & Wong, 2010) have noted that family-based interventions can reduce social impairment, encourage compliance with medication and reduce the incidence of relapse in PWS. These family-oriented strategies range from providing general information on the illness, care provision, to more comprehensive interventions that include psychoeducation, consultation, family interventions, and therapies (Pharoah et al., 2010; Walsh, 2021).

The literature identifies three essential needs required by family caregivers. First, they have *information-based needs* pertaining to a range of issues, such as the nature of the illness and its treatment, about caregiving and management issues, the mental health system, and available community resources. Second, *skill enhancement* strategies for coping with the illness, and its consequences for their family, and third, they need *support* for themselves (Marsh & Lefley, 2003).

Information and support needs can be met through psychoeducational approaches. Family psychoeducation programs are structured psychotherapeutic interventions that have been evidenced to lower relapse rates for PWS besides providing benefits for family members, such as improved relationships within and outside the family (Harvey, 2018). Family psychoeducation has been extensively evaluated and provides an evidence-based treatment approach in schizophrenia (Drake et al., 2001). It has also been suggested by Walsh (2021) that multifamily groups provide social support to one another, share practical information, offer guidance for stress reduction, crisis management, and problem solving, and enable one another to get a better grip on caregiving issues and the management of the PWS.

It has been shown that resilience and social support buffer against the negative effects associated with caregiving among family members (Magliano et al., 2002). Building resilience among family caregivers minimizes the impact of stressors on the family by maintaining constructive communication, fostering positive growth, strengthening family bonds, and providing the necessary social support (Lee, Koeske, & Sales, 2004). Family caregivers can be helped to regain their resilience through resilience-oriented family interventions, such as family support groups, community resources, and the provision of social support (Walsh, 2016). It has been further suggested that family consultations, brief intervention, or more intensive family therapy may benefit by combining individual and conjoint sessions that includes members most affected by stress along with those who can contribute to the development of their resilience (Walsh, 2021).

Several studies support the role of perceived social support as an interpersonal coping resource for family caregivers and an aspect that is significantly associated with their adaptation (Aggarwal, Avasthi, Kumar, & Grover, 2011, Mackay & Pakenham, 2011). It has been seen that social support correlates negatively with family burden and positively with stress coping (Stanley et al., 2016). The enhancement of social support and professional support are hence viewed as essential solutions to alleviate the burdens of caregivers of PWS (Ribé et al., 2018). Many programmes have been implemented to provide social support or professional support for people experiencing schizophrenia and their caregivers. It has been observed that traditionally in India, which has strong clan and kinship networks, reaching out to people outside the family for help was not considered in keeping with the cultural and family norms (Seshadri, Sivakumar, & Jagannathan, 2019). However, the evidence indicates that programs that have generated positive outcomes for patients and their family caregivers include “Family-to-Family Support Program” (Bademli & Duman, 2016), psychoeducation programs (Chan, Yip, Tso, Cheng, & Tam, 2009), and mutual support groups for family caregivers (Chien & Norman, 2009). Such targeted programs are woefully lacking in the Indian context, and it is suggested that institutions dealing with PWS may also focus attention on their caregivers to help alleviate caregiving stress and enhance resilience and life satisfaction.

It is noteworthy to observe that the National Mental Health Policy of India (2014) envisages support for families including “caring for the carer,” forming caregiver groups, providing financial support (including monetary and tax benefits) for caregivers, access to information, and assisted living services. It also advocates for the involvement of the family in designing, implementing, and monitoring mental health services. Welcome measures that if observed in letter and spirit will go a long way to ameliorate the plight of family caregivers on people with mental illness.

Directions for future research

Future studies may consider the use of a longitudinal design to ascertain if the changing dynamics of the caregiving relationship influence the manifestation of the variables being studied. More attention could also be paid to positive aspects associated with the discharge of the caregiving function, such as personal accomplishment and gratification, relationship mutuality and satisfaction, an enhanced family cohesion, feelings of personal growth and purpose in life.

Limitations

The cross-sectional design of the study limits our ability to draw cause-effect inferences. Further, given the cultural context in which the study has been carried out, the scope for generalizations of our findings is fairly limited. All relationships including the caregiving one are characterized by dynamic shifts and changes and this study may not have captured these interpersonal transitions. We also acknowledge the role of clinical features, such as symptom severity and treatment compliance that could potentially influence the demands on caregivers and this is another major issue that has not been considered in our investigation.

Conclusion

This study has turned the spotlight on the experience of family caregivers in looking after PWS. It points toward the need to strengthen resilience in them to enable them to deal more effectively with caregiving stress thereby enhancing their wellbeing and life satisfaction.

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