Experience of Caregiving and Coping in Caregivers of Schizophrenia

Nimisha Doval [1], Eesha Sharma [1], Manu Agarwal [1], Adarsh Tripathi [1], Anil Nischal [1]

Abstract

Background: Caregivers of schizophrenia play a major role in community-based care of patients. Recent studies have shed light on positive aspects of caregiving, in contrast to caregiving burden. There is limited research in this area in India. **Aims:** To assess the *"experience of caregiving"* and *"coping strategies"* in caregivers of patients with schizophrenia, and to study associations, if any, between them. **Method:** 102 caregivers of out- and in-patients with schizophrenia were assessed on the "Experience of Caregiving Inventory" (ECI) and "COPE Inventory" (COPE). Sociodemographic profiles of patients and caregivers, and clinical histories of patients were also collected. **Results:** Maximum perceived negative experience of caregiving was "effects on family" while "stigma" was the lowest. Other domains had moderate scores. Among positive experiences, "good aspects of relationship" scored higher than "positive personal experiences." A wide range of adaptive and maladaptive coping strategies were used. Statistically significant positive correlations emerged between positive experiences of caregiving and adaptive coping strategies, and between negative experiences of caregiving and maladaptive coping strategies. **Conclusion:** The association between experiences of caregiving and coping strategies suggests that caregiving experiences are influenced not only by the illness but also by the coping methods employed. Helping caregivers cope better might improve caregiving experience.

Key Words: Experience of Caregiving, Coping, Schizophrenia, Caregivers

Introduction

Schizophrenia is a debilitating psychiatric disorder, which not only influences the lives of those affected but also that of their family members. The usually chronic course of illness leads to social and occupational impairment, posing obstacles to independent living and life satisfaction (1). Presence of a person with a serious mental disorder creates a burden for the family, and can trigger psychological morbidity in individual family members or alter family dynamics. Institutionalized psychiatric care is now passé. Mental health systems worldwide seek to better the quality of patients' lives by providing care in the community, and integrating them back into society as soon as possible. This, however, leads to greater demands on the caregivers.

Numerous studies have examined burden of care (2-14). Several such studies have been conducted in India (5-8). These studies show that caring for a mentally ill relative is associated with a high level of stigma (9, 10) and feelings of loss and grief (11). Caregivers also face considerable financial, social, and emotional burden (12, 13). A major problem with the concept "burden of care" is that it portrays only the negative aspects of caregiving. It fails to take into account the role of personality and social support systems that could mitigate these negative effects. In addition, there is a paucity of data on positive influences that the caregiving role could have on the caregiver's life. In fact, some stud-

[1] *King George Medical University, Chowk, Lucknow, Uttar Pardesh, India*

Address for correspondence: Dr. Eesha Sharma, King George Medical University, Chowk, Lucknow, Uttar Pradesh, India - 226003
Phone: +91 7607644445; E-mail: eesha.250@gmail.com

Submitted: August 19, 2015; Revised: November 22, 2015;
Accepted: December 30, 2015

Clinical Implications

Caregivers of patients with schizophrenia bear a significant burden. However, like all difficult endeavors, caregiving, too, can have both negative and positive impact. Given the role caregivers can play in securing favorable outcomes for patients, it is important to understand how their experience of caregiving can be improved. In this context, our study has important findings. Caregivers of patients with schizophrenia have both positive and negative experience of caregiving, and they use a variety of coping strategies. While illness-related variables predominantly affect negative experience of caregiving, caregiver characteristics such as male gender, higher education, urban residence, and higher family income enhance positive experience. These characteristics help knowledge of, accessibility to, and affordability of care. Positive experience of caregiving increases when caregivers use more adaptive, and less maladaptive, coping strategies. Our study findings have implications for designing family interventions in patients with schizophrenia.

ies show that caregiving may be a source of self satisfaction, could strengthen family bonds, and lead to an overall positive transformation (14).

Szmukler et al. (15) viewed caregiving from a "stress-coping" paradigm, and conceptualized "experience of caregiving" as an analysis of the demands of caregiving. It takes into account the positive as well as the negative experience of caregiving. Studies, in fact, show that caregivers have both types of experience—positive and negative—as a result of caring for their ill relatives. Examples of positive experience include satisfaction with their caregiving experience, and a better ability to deal with difficult situations (14, 16, 17). An important determinant of the type of experience of caregiving could be the coping strategies used by the caregiver. Coping strategies have been broadly classified as "problem-focused coping" and "emotion-focused coping" (18). A study by Aggarwal et al. (19) showed that caregivers using adaptive coping strategies had a more positive experience of caregiving.

While several studies have been conducted in the west, data from India on experience of caregiving and coping strategies used by caregivers of schizophrenia patients are scarce. Caregivers' needs as well as experience differ across cultures (4). It would, therefore, be imprudent to generalize findings from the west to an Indian context. This study was designed with the aim of studying the "experience of caregiving" in caregivers of patients with schizophrenia. A secondary aim was to assess coping strategies used by caregivers and to study their association, if any, with the experience of caregiving.

Method

Sample

The sample was drawn from the outpatient service of the psychiatry department of a medical university in north India. Out of 230 patients with schizophrenia and their respective caregivers screened, 102 patient-caregiver pairs fulfilled selection criteria and were recruited for the study. Diagnosis of schizophrenia was made by consultant psychiatrists in the department. "Caregiver," for the purpose of this study, was defined as *"A family member of the patient, who is living with the patient in the same household, is spending time with the patient and shouldering responsibility of caring for the patient for most of the time."* In the patient-caregiver pairs included, the patients fulfilled the following inclusion criteria: 1) age 18–60 years, 2) diagnosis of schizophrenia as per *ICD-10 DCR* (20), and 3) duration of illness of at least one year. Caregivers fulfilled the following inclusion criteria: 1) age 18–60 years and 2) fulfilling the operational definition of caregiver. Patient-caregiver pairs were excluded if: 1) patient had a comorbid psychiatric disorder (other than nicotine use disorders), or any major medical/surgical disorder/disability, 2) caregiver had any current psychiatric/medical/surgical illness or disability that might interfere with caregiving, or 3) another family member suffering from a chronic physical or psychiatric illness dwelling in the same household. Written informed consent was obtained from both patient and caregiver. The Institutional Ethics Committee approved the study.

Procedure

One of the authors (ND) assessed the patient-caregiver pairs included in the study after obtaining written informed consent. All the assessments were carried out preferably on the same day as recruitment into the study, or on another mutually convenient day.

Instruments

Mini International Neuropsychiatry Interview version 6.0.0 (MINI) (21) was applied to screen for psychiatric illness in the caregiver, and for any comorbid psychiatric illness in the patient. Psychopathology in patients was assessed on the Positive and Negative Syndrome Scale (PANSS) (22). Szmukler et al.'s "Experience of Caregiving Inventory" (ECI) (15), and "COPE Inventory" (COPE) by Carver et al. (18) were used to assess the caregivers.

Experience of Caregiving Inventory (ECI), a 66-item self-report scale, identifies ten independent dimensions of appraisal of caregiving: eight negative dimensions ("difficult behaviors," "negative symptoms," "stigma," "problems with

Table 1 Sociodemographic and Clinical Profile of Patients (N=102)

Variable	Description	
Age (Mean±SD)		32.24±9.34 years
Sex [n (%)]	Male	68 (66.67)
	Female	34 (33.33)
Domicile [n (%)]	Rural	42 (41.18)
	Urban	60 (58.82)
Education [n (%)]	Illiterate	19 (18.63)
	Up to class 5	14 (13.73)
	Class 6 to 10	23 (22.55)
	Class 11 to less than graduate	16 (15.68)
	Graduate	21 (20.59)
	Postgraduate	9 (8.82)
Religion [n (%)]	Hindu	77 (75.49)
	Muslim	24 (23.53)
	Christian	1 (0.98)
Type of family [n (%)]	Joint	39 (38.24)
	Nuclear	63 (61.76)
Marital status [n (%)]	Married	43 (42.16)
	Never married	39 (38.24)
	Divorced/Separated	14 (13.72)
	Widow/Widower	6 (5.88)
Family income per month [n (%)]	Less than INR 5,000	45 (44.12)
	INR 5,001–10,000	15 (14.71)
	More than INR 10,000	42 (41.17)
Occupation [n (%)]	Unemployed	41 (40.20)
	Unskilled/Semiskilled	27 (26.47)
	Skilled	9 (8.82)
	Professional	2 (1.96)
	Housewife	23 (22.55)
Age at onset of illness (Mean±SD)		25.62 (7.17) years
Duration of illness (Mean±SD)		6.56 (6.75) years
Duration of untreated psychosis (Mean±SD)		1.67 (2.38) years
Subtype of schizophrenia [n (%)]	Paranoid	53 (51.96)
	Undifferentiated	49 (48.03)
PANSS* scores (Mean±SD)	Positive subscale	13.29 (7.29)
	Negative subscale	16.32 (5.74)
	General psychopathology subscale	27.68 (7.08)
	Total	**57.29 (16.92)**
Adherent to medication [n (%)]		60 (58.82)
Positive family history of psychosis [n (%)]		26 (25.49)
In remission† [n (%)]		58 (56.86)

*PANSS: Positive and Negative Syndrome Scale (Kay et al., 1987 [22]); †As per remission criteria given by Andreasen et al., 2005.

Table 2 Sociodemographic Profile of Caregivers (N=102)

Variable	Description	
Age (Mean±SD)		42.7±12.35 years
Sex [n (%)]	Male	34 (33.33)
	Female	68 (66.67)
Education [n (%)]	Illiterate	27 (26.47)
	Up to class 5	7 (6.86)
	Class 6 to 10	22 (21.56)
	Class 11 to less than graduate	19 (18.62)
	Graduate	20 (19.6)
	Postgraduate	7 (6.86)
Marital status [n (%)]	Married	84 (82.35)
	Never married	8 (7.85)
	Widow/Widower	10 (9.80)
Occupation [n (%)]	Unemployed	8 (7.84)
	Unskilled/Semiskilled	33 (32.35)
	Skilled	11 (10.79)
	Professional	5 (4.90)
	Housewife	45 (44.12)
Relationship to patient [n (%)]	Mother	43 (42.16)
	Wife	21 (20.59)
	Husband	21 (20.59)
	Father	5 (4.90)
	Son	4 (3.92)
	Sister	3 (2.94)
	Brother	3 (2.94)
	Daughter	1 (0.98)
	Uncle	1 (0.98)

services," "effects on the family," "loss," "dependency" and "need for back up") and two positive dimensions ("positive personal experience" and "good aspects of the relationship with the patient"). The items in these dimensions are rated on a Likert scale (0=never; 1=rarely; 2=sometimes; 3=often; 4=nearly always). The negative and positive dimension scores can be summed up to give total negative appraisal (ECI-neg) and total positive appraisal (ECI-pos) scores.

COPE Inventory (COPE), comprising 15 subscales, is a multidimensional inventory to assess ways in which people respond to stress. The items are rated on a Likert scale (1=I usually don't do this at all; 2=I usually do this a little bit; 3=I usually do this a medium amount; 4=I usually do this a lot). The subscales can be differentiated into "adaptive or functional" coping (positive reinterpretation and growth, active coping, suppression of competing activities, planning, use of instrumental social support, restraint, religious coping, use of emotional social support and humor), and "maladaptive or dysfunctional" coping (mental disengagement, focus on and venting of emotions, denial, behavioral disengagement, and substance use) (18). "Acceptance" is a coping strategy that may be considered either adaptive or maladaptive depending on the context (18).

Statistical Analysis

Means, standard deviation and frequencies were calculated for sociodemographic and clinical variables. Pearson's correlational analysis was used to assess the association between continuous variables. Independent samples t-test and analysis of variance (ANOVA) were used for group comparisons.

Table 3 Scores on the Experience of Caregiving Inventory

Variable		Score [Mean (SD)]	Range
Negative subscale	Effects on family	12.95 (4.41)	0–28
	Negative symptoms	12.35 (4.54)	0–24
	Difficult behavior	11.85 (7.20)	0–32
	Dependency	11.81 (3.27)	0–20
	Loss	11.52 (3.84)	0–28
	Need to back up	10.96 (3.87)	0–24
	Problem with services	10.68 (4.06)	0–32
	Stigma	8.67 (4.26)	0–20
	TOTAL NEGATIVE SUBSCALE SCORE	**90.79 (22.12)**	**0–208**
Positive subscale	Good aspects of relationship	13.67 (3.81)	0–24
	Positive personal experiences	11.85 (5.67)	0–32
	TOTAL POSITIVE SUBSCALE SCORE	**25.33 (9.38)**	**0–56**

Results

Sociodemographic and Clinical Profile

The mean age of patients was 32.24±9.34 years and that of caregivers was 42.7±12.35 years. Whereas the majority of patients were male (66.67%), the majority of caregivers were female (66.67%). Most of the caregivers were mothers of the patients (42.16%), followed by equal percentages of wives (20.58%) and husbands (20.58%). The sample was largely Hindu (75.49%), and from an urban (58.82%), nuclear family (61.76%) background, with a low monthly family income (less than 5,000 Indian rupees) (44.12%). About 40% of the patients were unemployed; and 38.24% of them were never married. In our sample, the mean age at onset of schizophrenia was 25.62±7.17 years, mean duration of illness was 6.56±6.75 years, and the mean duration of untreated psychosis was 1.67±2.39 years. Mean total PANSS score was 57.29±16.92, indicating an overall mild severity of illness. However, less than half (43.14%) of the patients were in remission (according to criteria proposed by Andreasen et al. [2005]). Majority of patients had Paranoid (51.96%) or Undifferentiated (48.03%) schizophrenia. Adherence to medication, assessed by the caregivers' verbal report, was maintained in 58.82% of the patients. Around 25% of the patients had a family history of psychosis. See Tables 1 and 2.

Assessment of Caregivers on Experience of Caregiving Inventory

All the caregivers reported both positive and negative experience of caregiving. The mean ECI-neg score was 90.79±22.12 (maximum possible score being 208) and the mean ECI-pos score was 25.33±9.38 (maximum possible score being 56). Among the ECI-neg dimensions, "effects on family" scored the highest while "stigma" had the lowest score. Among the ECI-pos dimensions, "good aspects of relationship" scored higher than "positive personal experience." Analysis of sociodemographic variables revealed that caregiver education (r=0.624; p=<0.001) and family income (r=0.502; p=<0.001) were associated with ECI-pos scores. It was interesting to see that wives had higher ECI-pos scores than mothers or husbands (F=3.46; p=0.04). Also, ECI-pos was greater in those residing in urban areas (t=-3.283; p=0.002). On comparing experience of caregiving between male and female caregivers, we found that while males had higher ECI-pos scores (t=2.042; p=0.046), female caregivers had higher ECI-neg scores (t=-2.43; p=0.04).

Analysis of clinical variables revealed interesting associations with ECI-neg scores. While PANSS total and subscale scores had a positive correlation with ECI-neg scores (PANSS total score [r=0.624; p=<0.001], PANSS positive scores [r=0.559; p=<0.001], PANSS negative score [r=0.416; p=<0.001], and PANSS general psychopathology score [r=0.578; p=<0.001]), duration of illness had a negative correlation (r=-0.200; p=0.04). In addition, ECI-neg scores were higher when patients were not in remission (t=-5.09; p=<0.001) and not adherent to medication (t=-4.11; p=<0.001). See Table 3.

Assessment on COPE Inventory

Assessment on COPE Inventory revealed that caregivers used both adaptive and maladaptive coping strategies, and that the use of multiple coping strategies, in various combinations, was the norm. "Religion," "use of instrumental social support," "restraint," "suppression of competing activities," "positive reinterpretation and growth," "planning," and "use of emotional social support" were the adaptive coping strategies being used by the caregivers. Each of these was reported by at least 70% of the caregivers. Similarly, more

Table 4 Scores on the COPE Inventory

Variable		Score [Mean (SD)]	Range
Adaptive coping strategies	Religion	10.83 (2.25)	4–16
	Use of instrumental social support	10.72 (1.92)	4–16
	Positive reinterpretation and growth	10.42 (2.26)	4–16
	Restraint	10.20 (2.27)	4–16
	Planning	10.14 (2.46)	4–16
	Active coping	10.14 (2.25)	4–16
	Suppression of competing activities	10.05 (1.80)	4–16
	Use of emotional social support	9.91 (2.67)	4–16
	Humor	6.31 (3.22)	4–16
Maladaptive coping strategies	Acceptance	10.64 (1.76)	4–16
	Focus on and venting of emotions	9.90 (2.79)	4–16
	Mental disengagement	9.40 (2.17)	4–16
	Behavioral disengagement	9.01 (3.04)	4–16
	Denial	5.54 (2.38)	4–16
	Substance	5.32 (2.51)	4–16

Table 5 Pearson's Correlational Analysis Between Scores on Experience of Caregiving Inventory and Scores on COPE Inventory*

COPE subscale → **ECI subscale** ↓	**ESS** [r (p)]	**FVOE** [r (p)]	**MD** [r (p)]	**BD** [r (p)]	**D** [r (p)]	**AC** [r (p)]	**H** [r (p)]	**P** [r (p)]	**PRG** [r (p)]	**SCA** [r (p)]
ECI-Neg	0.397 (<0.001)	0.467 (<0.001)	0.342 (<0.001)	0.474 (<0.001)	0.258 (<0.01)	NS	NS	NS	NS	NS
ECI-Pos	-0.210 (0.03)	NS	-0.273 (<0.01)	-0.246 (0.01)	-0.201 (0.04)	0.596 (<0.001)	0.215 (0.03)	0.428 (<0.001)	0.567 (<0.001)	0.243 (0.01)

*This table depicts only the statistically significant correlations. Columns marked "NS" indicate that the correlation was not significant.

ECI-Neg: total score on negative subscale of ECI; ECI-Pos: total score on positive subscale of ECI; ESS: Emotional Social Support; FVOE: Focus on and Venting Of Emotions; MD: Mental Disengagement; BD: Behavioral Disengagement; D: Denial; AC: Active Coping; H: Humor; P: Planning; PRG: Positive Reinterpretation and Growth; SCA: Suppression of Competing Activities; r=Pearson's correlation coefficient; p=p-value.

than 70% of caregivers reported "acceptance." Maladaptive coping strategies—like "focus on and venting of emotions," "mental disengagement," and "behavioral disengagement"—were also reported by nearly 70% of the caregivers. Lesser-used adaptive coping strategy was "humor," while lesser-used maladaptive coping strategies were "substance use" and "denial," each of which was reported by less than 30% of the caregivers. See Table 4.

Association Between Coping Strategies and Experience of Caregiving

ECI-neg scores correlated with several maladaptive coping strategies (denial [r=0.258; p=<0.01], focus on and venting of emotions [r=0.467; p=<0.001], mental disengagement [r=0.342; p=<0.001], and behavioral disengagement [r=0.474; p=<0.001]). ECI-pos scores correlated with several adaptive coping strategies (active coping [r=0.596; p=<0.001], planning [r=0.428; p=<0.001], positive reinterpretation and growth [r=0.567; p=<0.001] and suppression of competing activities [r=0.243; p=0.01]). Interestingly, ECI-pos scores also had a negative correlation with maladaptive coping strategies (mental disengagement [r=0.273; p=<0.01], behavioral disengagement [r=0.246; p=0.01] and denial [r=-0.201; p=0.04]). Thus, adaptive coping was associated with positive experience of caregiving, whereas maladaptive coping was associated with negative experience of caregiving. See Table 5.

Discussion

The family plays an extremely important role in the care of patients with schizophrenia. Expressed emotions, which have the potential to affect the long-term course and outcome of illness (23, 24), probably stem from experience of caregiving, which in turn might be determined by coping strategies adopted by the caregivers. In the present study, experience of caregiving and coping strategies were assessed in 102 caregivers of patients with schizophrenia. The sociodemographic and clinical profile of the patients included in this study is representative of the majority of treatment-seeking outpatients with schizophrenia.

It is interesting to see that all caregivers had negative as well as positive experience of caregiving. This reiterates the fact that caregiving does not essentially imply negative effects alone. The ECI-neg scores observed in this study are comparable with scores reported by earlier studies (15, 19, 25, 26). High scores on "effects on family," "dependency," and "need for back-up" are understandable, given that the majority of patients in this study were young, unemployed males from nuclear families. This would have obvious socioeconomic disadvantages for the whole family. Scores on the "loss" domain of ECI probably reflect the feeling of having lost the person that the patient could have been had he not fallen ill. Relatively low scores on the domain "difficult behaviors" can be understood in the background of overall low positive psychopathology scores on PANSS. Aggarwal et al. (19) reported high scores on "difficult behavior," given that their sample had higher scores on the PANSS positive subscale. The relatively high scores on the "negative symptom" domain reflect the common observation that negative symptoms persist after remission of positive symptoms, and can impair socio-occupational functioning. The caregivers in our study had low scores on "problems experienced with services" and "stigma." This could be due to the fact that most caregivers were educated, and may have adequate understanding of the condition and accessibility to care. However, we acknowledge the fact that this being a clinic-based study, and the investigators part of the treating teams, socially desirable responses may have been given.

Low scores on stigma is an unusual finding in this study as earlier studies reported high stigma associated with caring for a mentally ill relative (9, 10). Patients in this study had been ill for almost 7 years, and were, at the time of assessment, only mildly symptomatic. Adjustment to the patient's illness over time and hope for benefit from further treatment, might have affected the perceived stigma. Among the positive experience of caregiving, caregivers perceived "good aspects of relationship" more often than "positive personal experience." "Good aspects of relationship" includes the feeling of having contributed to the well-being of the patient, acknowledging the patient's strengths, acknowledging the contribution of the patient in the household and sharing interests of the patient. Our findings are in agreement with those of Aggarwal et al. (19), Tarricone et al. (27), and Jorge and Chaves (26).

Analyses to study the association between experience of caregiving and sociodemographic and clinical characteristics found that education of the caregiver, family income, and urban residence were associated with higher positive experience of caregiving. These findings suggest that educated, economically secure caregivers, residing in urban areas, who are more likely to have knowledge of—and access to—care, have greater positive experience of caregiving. There were gender differences in experience of caregiving, in that males had higher positive experience while females had higher negative experience. Majority of female caregivers were housewives who spent most of their time with the patient, getting few or no breaks at all. This may lead to a feeling of physical/emotional fatigue and a greater likelihood of developing expressed emotions, such as overinvolvement, which might explain these findings.

Analyses to study association between experience of caregiving and clinical variables revealed that negative experience of caregiving had a positive correlation with PANSS scores and was higher when the patient was either nonadherent to treatment or not in remission. Thus, symptomatic status has a negative impact on the experience of caregiving, and adequate control of symptoms might improve caregiving experience. Surprisingly, duration of illness inversely correlated with negative appraisal (i.e., as the duration of illness increased, the negative experience of caregiving decreased) (28). It is plausible that the reduction of positive and disorganization symptoms, over the long course of illness, has a moderating influence on negative experience of caregiving. It is also possible that, with time, a caregiver learns to handle the problems associated with caregiving, accepts the situation and the negative experience consequently reduces. Notably, previous studies (29) have not reported any association between the duration of illness and experience of caregiving.

It is interesting to note the differential association of experience of caregiving: negative experience of caregiving was associated with clinical variables of the patient whereas positive experience of caregiving was associated with sociodemographic variables of the caregivers. This could imply that while the burden of illness affects negative experience, caregiver-related factors affect positive experience.

Association Between Coping Strategies and Experience of Caregiving

The caregivers assessed in our study were using both adaptive and maladaptive coping strategies. With the exception of humor, denial and substance use, each of the coping strategies were being used by a majority (>70%) of the caregivers. The duration of illness of patients in this study varied from 1 to 35 years. Coping strategies may change over time, and this possibly accounts for the large variety of strategies observed in our sample.

The second aim of this study was to examine the association between coping strategies and experience of caregiving. We found that a negative experience of caregiving was associated with greater use of maladaptive coping strategies, implying that caregivers who do not cope well have more negative caregiving experience. Positive experience of caregiving was associated with greater use of adaptive coping strategies and lower use of maladaptive coping strategies, implying that effective coping makes caregiving experience positive. Thus, helping caregivers identify their maladaptive coping strategies and changing them to adaptive coping strategies could increase the positive experience of caregiving. This would, in turn, go a long way in reducing expressed emotions and improving patient outcomes (23, 24).

Conclusion

Caregivers of patients with schizophrenia bear a significant burden. However, like all difficult endeavors, caregiving, too, can have both negative and positive impact. Given the role caregivers can play in securing favorable outcomes for patients, it is important to understand how their experience of caregiving can be improved. In this context, our study has important findings. Caregivers of patients with schizophrenia have both positive and negative experience of caregiving, and they use a variety of coping strategies. While illness-related variables predominantly affect negative experience of caregiving, caregiver characteristics such as male gender, higher education, urban residence, and higher family income enhance positive experience. These characteristics help knowledge of, accessibility to, and affordability of care. Positive experience of caregiving increases when caregivers use more adaptive, and less maladaptive, coping strategies. Our study findings have implications for designing family interventions in patients with schizophrenia.

Limitations of the Study

We acknowledge several limitations in our study. The sample was mixed (i.e., included both actively symptomatic and relatively stable patients). The functioning of the patients was not assessed. The symptom and functioning status of the patients could impact caregiving experience, as it was found in this study that negative experiences of caregiving was greater in unremitted patients. The psychological morbidity and functioning of the caregiver was not assessed. It is understandable that a depressed caregiver, for example, would report more negative experience of caregiving. The MINI picks up psychiatric disorders, but is not sensitive to subsyndromal psychopathology that could impact quality of life and, in this case, caregiving experience. The scales used do not have pre-defined cut-offs for interpretation, limiting us to correlational analysis. Cross-sectional assessments would fall short of picking up longitudinal variations in a dynamic concept like experience of caregiving. A validation exercise was not carried out for the Hindi- translated versions of the scales. The study did not include a control group. Thus, we cannot say in the present study whether the caregiving experience in schizophrenia differs from other illnesses.

Several factors can affect caregiving experience, and a caregiver's role can be an important determinant in the long-term outcome of illness. This area, thus, merits further research. Comparison of caregiving experience across illnesses, and caregiving experience over the longitudinal course of an illness would help shed light on this dynamic concept. Studies in the future should factor in the limitations of the present work.

Acknowledgments

This study was done as Dr. Nimisha Doval's dissertation, part of post-graduation (MD) in Psychiatry, at the King George Medical University, UP, Lucknow, India. *Through this work we especially want to express gratitude to our revered teacher, late Prof. J K Trivedi, who conceptualized and nurtured this idea, and ushered us into research in this area. Without his guidance this work would not have seen the light of day.*

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