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# Caregiving Stress among Caregivers of Patients admitted with Suicidal Attempt

Prekshya Thapa,[1] Sami Lama,[1] Nirmala Pradhan,[1] Kriti Thapa,[1] Rajesh Kumar,[2] Madhur Basnet[2]

## ABSTRACT

**Background:** Family caregivers play a key role in preventing suicide attempts. The objective of this study was to study the caregiving stress of the patients admitted with suicide attempt at a tertiary care hospital in Nepal.

**Methods:** A mixed method study was conducted with 52 family caregivers of suicidal people who had been admitted at B. P. Koirala Institute of Health Sciences, Dharan with history of suicide attempt. Data were collected through interview using Kingston Caregiver Stress Scale and in-depth interview was conducted on five family caregivers using interview framework developed in the department for the purpose.

**Results:** The mean caregiving stress score was 29.84(SD=5.11), with the mean score of score 22.0 (±3.9) in caregiving issues, 4.3(±1.9) in family issues and 3.5(±0.9) in financial issues respectively. Majority (65.4%) of the caregiver had perceived stress scores above the mean score. Caregiver's stress was significantly associated with age (p= 0.023), marital status (p= 0.008) and patient's mode of attempt (p=0.035) with stress level being higher in those with older age, married and hanging as the mode of suicide attempt. In-depth interview showed that financial difficulties, emotional and physical problems, difficulty maintaining daily activities, and stigma related problem seem to significantly increase caregiver's stress.

**Conclusions:** The study showed overall stress level of caregivers was high.

**Keywords:** Caregiver; stress; suicide attempter

## INTRODUCTION

Suicide is a significant public health problem[1] with over 800,000 suicides every year and many more attempted suicide.[2] WHO reported age-standardized suicide rate of 9.8 per 100,000 population for Nepal in 2019.[3,4] Caregiver stress refers to a "psychological state produced by the combination of physical work, emotional pressure, social restrictions, and economic demands arising from taking care for a patient."[5,6]

Because of lack of formal type of caregiving in Nepal, major responsibility of caregiving is shouldered by family members.[7] Studies show that caregivers of suicidal patient feel 'impending burnout',[8,9] while they are also ashamed of seeking help because of the tremendous stigma surrounding suicide.[10,11] As most research on suicide focus on suicidal individual, there is a deficit of research regarding caretaking of suicidal individuals.[8] This study aims to find out the level of stress among caregivers of suicidal patients and various factors associated with it.

## METHODS

A Mixed Method study design as "concurrent QUANT_qual" was conducted among 57 caregivers of patients with suicidal attempt meeting the eligibility criteria who were admitted in various wards of BPKIHS from December 2016 to June 2017. The quantitative and qualitative data were collected at the same time and the methodology was primarily quantitative. Quant_qual methodology was used to supplement the findings of Quantitative method by those of qualitative method as caregiving also includes lot of subjective aspects that might not be reflected by quantitative method only. All caregivers who were above 18 years of age and caring for the patients with suicidal attempt admitted in various wards of BPKIHS and who were referred to psychiatry department for evaluation were eligible for participation. Only those caretakers who had been with the patient continuously for at least six months and had been taking the primary responsibility of the patient were considered as the caregivers for the study. Those caregivers who were diagnosed with mental or

**Correspondence: Prekshya Thapa, Department of Psychiatric, B. P. Koirala Institute of Health Sciences, Dharan, Nepal. Email:prekshya.thapa90@gmail.com, Phone: +9779851194274.**

other chronic illness were excluded. 57 consecutive participants were enrolled out of five were used for pretest and thus excluded in the final analysis. Five of the caregivers were taken for in-depth interview.

Ethical clearance was obtained from the Institutional Review Committee of BPKIHS (IRC/0797/016). An informed consent was read to the caregivers and once the consent was signed, a face to face interview was conducted using pretested structured questionnaires. All the points of good clinical practice and ethical research were duly followed throughout the study.

Kingston Caregiver Stress Scale (KCSS), a five point likert scale, was used to assess caregiver stress.[12] As the scale has not been validated in Nepali, we translated the scale into Nepali using the standard protocol for translation and content validation was done in consultation with the content experts. Total items in the scale are 10 consisting of 3 subscales: caregiving issues (1-7), family issues (8-9) and financial issues (10).For in-depth interview, the two open ended questions were asked to the caregivers (Table 4). The interview were collected using interview schedule guide in the respective wards or psychiatry OPD in separate room maintaining confidentiality and comfort by the lead author herself. The total time taken was around 45- 60 minutes. All the interviews were audiotaped and later on transcribed.

After collection of data, they were organized, coded and entered into Microsoft EXCEL and converted into SPSS 21.0 version. Descriptive(frequency, median, mean, Standard Deviation and percentage) and inferential statistics(Independent T- test and One way ANOVA) taking 95% confidence, 5% permissible error and p value of 0.05 were used to analyze the data. For qualitative analysis, all the interviews were audio-taped and transcribed verbatim. Each written interview transcript was examined for statements, major statements were extracted from the descriptions and meanings were formulated from the significant statements. The formulated meanings were sorted and then organized into categories, theme clusters, and themes to identify the experiences common to all participants with consensus among all the investigators.

## RESULTS

More females (54%) had attempted suicide while the gender wise distribution of the caregivers was almost equal (females, 48.1%). Majority of the caregivers (66.6%) as well as patients (65.4%) were hindu by religion. Siblings (34.6%), parents (26.9) and spouse (17.3%) were the main caregivers. Similarly, majority of caregivers (57.7%) as well as patients (59.6%) were from joint family. Most (76.9%) of the patients had chosen "self-poisoning" as the mode of attempt. Further details of socio-demographic characteristics is shown in Table 1.

Majority (65.4%) of the respondents had perceived stress scores above the mean (29.84) scores. The total mean stress score was 29.84(±5.11), with the mean score of 22.0 (±3.9) in caregiving issues, 4.3(±1.9) in family issues and 3.5(±0.9) in financial issues respectively (Figure 1). Caregiver score on individual statements of KCSS is shown in Table 2.

Caregiver's stress was significantly associated with age of the caregiver (p= 0.023), marital status (p= 0.008) and patient's mode of attempt (p=0.035). Stress level was higher in those caregivers with older age, who were married and whose patients had hanging as the mode of suicide attempt (Table 3).

Table 1. Socio-demographic characteristics of the caregivers and patients (N=52).

| Characteristics | Category | n(%) | |
|---|---|---|---|
| | | Caregivers | Patients |
| Age(in years) | Upto 20years | 7(13.5) | 16(30.8) |
| | 21-40 years | 26(50.0) | 28(53.8) |
| | >40 years | 19(36.5) | 8(15.4) |
| Mean age (SD) | | 36.0 (11.23) | 28.2 (12.3) |
| Marital status | Married | 45(87) | 30(57.7) |
| | Unmarried | 7(13) | 16(30.8) |
| | Divorced/ Widow/ Widower | 0 | 6(11.5) |
| Education level | Illiterate | 5(9.6) | 9(17.3) |
| | Can read and write only | 22(42.3) | 5(9.6) |
| | Primary level | 13(25.0) | 13(25.0) |
| | Secondary level and above | 12(23.1) | 25(48.1) |
| Occupation | Homemaker | 17(32.69) | 14(26.9) |
| | Agriculture | 8(15.38) | 8(15.4) |
| | Students | 0 | 13(25.0) |
| | Service/Jobs | 8(15.38) | 5(9.6) |
| | Others | 19(36.55) | 12(23.1) |

Table 2. Caregiver Stress score on individual statements of KCSS (N=52).

| Kingston Caregiver stress scale (KCSS) | Mean (SD) | Median |
|---|---|---|

| | | |
|---|---|---|
| Are you having feelings of being overwhelmed, overworked, and/or overburdened? | 3.40 (0.91) | 4.0 |
| Has there been a change in your relationship with your spouse/ relative? | 2.33 (1.10) | 3.0 |
| Have you noticed any changes in your social life? | 2.83 (0.83) | 3.0 |
| Are you having any conflicts with your previous daily commitments (work/volunteering)? | 3.58 (0.78) | 4.0 |
| Do you have feelings of being confined or trapped by the responsibilities or demands of caregiving? | 3.35 (0.93) | 3.0 |
| Do you ever have feelings related to a lack of confidence in your ability to provide care? | 2.87 (1.01) | 3.0 |
| Do you have concerns regarding the future care needs of your Spouse/ Relative? | 3.63 (0.74) | 4.0 |
| Are you having any conflicts within your family over care decisions? | 2.13 (1.12) | 2.0 |
| Are you having any conflicts within your family over the amount of support you are receiving in providing care? | 2.21 (0.96) | 3.0 |
| Are you having any financial difficulties associated with caregiving? | 3.52 (0.92) | 4.0 |
| Total Score | 29.84 | 31.00 |

Table 3. Association between caregiver's KCSS score and socio-demographic variables of caregivers and patients (N=52).

| Characteristics | Category | Caregiver Mean KCSS Score (SD) | p | Patient Mean KCSS Score (SD) | p |
|---|---|---|---|---|---|
| Age (in years) | Up to 20years | 27.4 (7.1) | | 29.8 (4.5) | |
| | 21-40 years | 28.7 (5.2) | 0.023* | 29.9 (5.5) | 0.99* |
| | >40 years | 32.3 (3.1) | | 29.9 (5.5) | |
| Marital Status | Married | 30.6 (4.6) | | 30.0 (5.0) | |
| | Unmarried | 25.1 (6.2) | 0.008** | 29.8 (4.7) | 0.906* |
| | Widowed/ divorced | 0(0) | | 29.0 (7.6) | |
| Mode of Suicide Attempt | Self-poisoning | 29.0 (5.1) | | | |
| | Hanging | 34.5 (2.6) | 0.035** | | |
| | Others | 32.0 (3.6) | | | |

*Note: * One way ANOVA ** T test*

Table 4. Major themes identified from indepth interview

| | | |
|---|---|---|
| Question | Can you please tell me about the changes in your life because you have been caregiver for the suicidal client? | What kind of help do you feel you need to make the care giving task easier? |
| Themes Identified | Shortage of money | Financial support(Free treatment services) |
| | Emotional issues<br>- Stress of having to be vigilant<br>- Worry<br>- Feeling depressed | Physical Facilities of hospital<br>- Canteen facility<br>- Separate washrooms<br>- Visitor rooms |
| | Physical problems<br>- Headache, Backache<br>- Lack of sleep<br>- Cough and cold | • Education and emotional support for caregivers |
| | Difficulty maintaining daily activities<br>• Timetable for food<br>• Self care<br>• Disruption of previous rountine | |
| | Stigma Related Problem | |
| | Positive experience<br>- Caring attitude of health professional | |

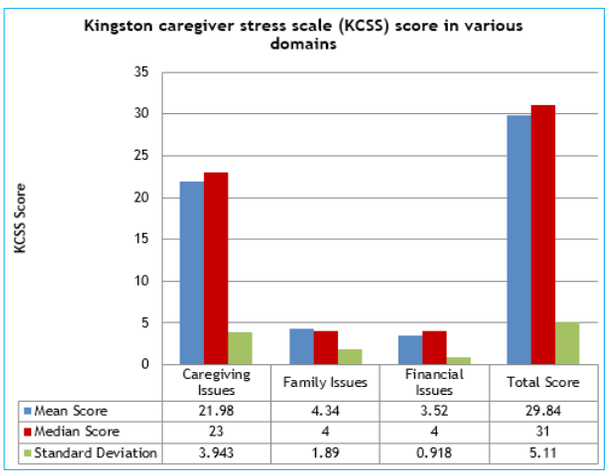


Figure 1. Caregiver stress on various domains (N=52).

**Experience of caregiving and effects on health of caregivers were:**

Shortage of money: The most commonly reported issue while caring for the patients was financial difficulty. *"We have to count the money to see if it will be enough or not."(IDNo.1) "I could have earned if I could go from here and that's the kind of problem happening."(IDNo.5) "There is no money at home also and they are sending by borrowing."(IDNo.4)*

Emotional Difficulty: Worry, tension, stress of having to be vigilant all the time to prevent suicidal attempt (*"Anytime have to be alert regarding where she would go and when."-IDNo.1; "I also have worry whether he would do something even when I go to bring medicine."-IDNo.2*, feeling depressed (*"I am feeling like I myself might getdepression."-IDNo.2)* and worry about the future (*Now whether she will be able to settle in her family or not is also a tension for us."-IDNo.1)* were some of the commonly felt emotions.

Physical Problems (Effect on Physical Health): Headache (*"I never had headache problem before but after coming here have been having lots of headache."-IDNo.1)*, lack of sleep (*I could not sleep for 2-3 days seeing everybody here."-IDNo.3)*, having cough and cold (*"I have been coughing and coughing because of the cold.-IDNo.5)*, backache and feeling of unwell (*"Since staying here, I have been having cold, backache, feeling like unwell."-IDNo.2)* were some of the commonly reported physical problems.

Difficulty maintaining daily activities: The caregivers expressed various difficulties in maintaining their daily routines including getting food on time (*"Don't have timetable for food."-IDNo.1),* difficulty falling asleep *("Tonight, I could not sleep whole night as patient shouted whole night."- IDNo.2),* difficulty maintaining self-care and maintaining hygiene (*"I could not bathe on time, wash clothes and so have to wear same clothes for three four days."- IDNo.3)* and disruption of their previous daily routines (*"There's a lot of work at home, in hills we have to work, work in the fields, look after the cattle, got goats too. I have come here leaving back all those. "-IDNo.5).*

Stigma Related Problems: Some of the caregivers also expressed that stigma towards patients also had made them feel difficult. *"Day before when I was coming in the auto, the driver asked where we were going and when I replied "mental ward" he said "that place where lunatics are kept?" I felt very bad that time."-IDNo.1*

Positive Experience: The caring attitude of the doctors and the nurses involved in the care of patients not only towards patients but also towards the caregivers were noted as one of such positive experiences. *"But two times doctor told me that 'you all attendants/ caretakers are under our vigilance, we will help you as well'." IDNo.1* Another caregiver expressed *"Like, in the village, people with such symptoms of mental illness are taken to faith healers. Now I realized, it's not like that, these are the symptoms of illness and have to take them to hospital." IDNo.3*

Making caregiving task easier:

Financial Support: Caregivers expressed that as the money needed to be paid out of pocket, it would be difficult to pay if hospital stay is prolonged. So, it would be better if treatment could be free *"Regarding money, it would be even better if treatment could be free."-IDNo.2 "Even for a middle class family, if one needs to stay long, it would be quite difficult."-IDNo.1*

Physical facilities of hospital: The caregivers expressed that improving hospital facilities like clean and separate bathrooms for males and females (*"Let the bathrooms be clean. Gents also come and they need to be notified not to go to female toilet.-IDNo.1),* separate place to sleep for caregivers and separate place for ladies to change clothes (*"There should be a separate place for the attendants also to sleep and place for ladies like us to change clothes."-IDNo.2*), better and cheaper canteen facility (*"In the canteen inside, food is too costly and it would be better if that could also be addressed."-IDNo.3)* would help ease their stress of caregiving further.

Education and emotional support for the caregivers: The caregivers also expressed that having learnt about the illness of their relatives helped them greatly and expressed that if there be a system for regular and further education and emotional support to them in the hospital, it could greatly help them cope with the caregiving stress and care their patients better. *"We have benefitted from learning about our relative's problem but I think we need further and regular training about our patient. There should be training about things like what is the illness, what needs to be done etc."-IDNo.1*

## DISCUSSION

While analyzing the socio-demographic characteristics of the patient, it revealed that the mean age of the suicidal patient belong to 18-30 age group which may be because of combination of developmentally

incomplete psychological coping mechanisms at a time when many of life's major stressors are encountered for the first time making the younger people at a unique psychological vulnerability. The proportion of female patients was slightly higher and married which may be because young females in developing countries are more vulnerable to various stressors[13], which resonates with other studies.[14, 15] In Nepal, it is not uncommon for women to have forced marriages, marry at a young age, and to have a large age gap between husband and wife. Since divorce is highly stigmatized, there is often social and familial pressure to stay married even in an abusive or unhappy relationship.[16] Most of the patients have chosen self-poisoning with pesticide/insecticide as a method of attempt which may be due to easy availability.[17,18] Majority (65.4%) of the respondents had perceived stress scores above the mean (29.84) scores which was consistent to the findings conducted by other studies.[19,20] In-depth interview showed that financial difficulties, emotional and physical problems, difficulty maintaining daily activities, stigma related problem seem to significantly increase caregiver's stress which are consistent with the findings of other studies.[21] Caregiver's stress was significantly associated with the age. This could be because with increasing age, one might be burdened by multiple responsibilities as well as have feeling of more responsibility towards the suicidal patient. However some other studies found no significant association with age.[15] Caregiver's stress was significantly associated with the marital status of the caregiver as majority of the caregivers were parents and spouse of the suicidal patients. Caregiver's stress was also significantly associated with patient's mode of attempt (p=0.035). This could be because of the fact that hanging is perceived as more lethal means of suicide. During in-depth interview, all the patients had expressed about financial difficulty which closely matches with the high mean score on financial difficulty in KCSS (mean/median= 3.52/4.00). All the participants had complained of being overwhelmed and overburdened because of caregiving responsibility and it is also consistent with the high KCSS score (mean/median=3.40/4.00). Likewise, there were high scores in concerns regarding the future care needs of the suicide attempter (mean/median=3.63/4.00) and feelings of being trapped or confined by the responsibilities or demands of caregiving (mean/median=3.35/3.00). All of the caregivers had expressed their concerns and worries about the risk of repetition of the act and the need of 24hours vigilance after going home. Overall, the findings of the in-depth interview complemented the findings of the quantitative study and it also helped us to get further in-sights about the caregivers' experiences of caregiving. Thus although KCSS has not been validated in Nepali, it could be used for assessment of caregiver stress in Nepal. Through the use of qualitative study we also came to know the in-depth experiences of caregiver with regards hospital facilities and health care providers' behavior towards them which seem to significantly affect their stress level and strategies to address caregiving issues.

## CONCLUSIONS

This study finding revealed that caregiver's stress was high and was significantly associated with age, marital status of the caregivers and with patient's mode of attempt. Financial burden had contributed a lot towards increasing the caring stress as well as the difficulties faced in maintaining personal hygiene and proper sleeping place exacerbated the problem further. Showing concerns, at least verbally and trying to note their stress by the health care workers were reported to result in feeling of relief by the caregivers.

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**Author Affiliations**

[1]Department of Psychiatric Nursing, College of Nursing, B. P. Koirala Institute of Health Sciences, Dharan, Nepal

[2]Department of Psychiatry, B. P. Koirala Institute of Health Sciences, Dharan, Nepal.

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