

Research Paper

The Impact of Self-Stigma of Seeking Help on Stress Perceived by Family Caregivers of COVID-19 Patients: A Mixed Method Approach

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ABSTRACT

This study aimed to assess the impact of self-stigma of seeking help (SSOSH) on the perceived stress (PS) of family caregivers of COVID-19 patients. The sample size for quantitative and qualitative phases of the study was 89 and 12 participants respectively. The participants filled a socio-demographic detail sheet and then completed self-report measures like Perceived Stress Questionnaire (PSQ) and Self-Stigma of Seeking Help (SSOSH). A semi-structured interview was conducted to understand patterns of caregiving, perceived stress, self-stigma and help-seeking among family caregivers of COVID-19 patients. Thematic analysis was conducted on the qualitative data. In the study, females reported a higher mean perceived stress whereas male participants reported a higher SSOSH score. The results indicated a significant positive correlation between SSOSH and PS. Through regression analysis, a significant impact of SSOSH on perceived stress among COVID-19 family caregivers was established. The qualitative themes point to the psychological impact, physical distress, post-COVID experiences, coping and social support systems, along with the help-seeking behaviours among them. The results from this study can be used for developing programmes to tackle caregiving stress and burnout by providing intervention on self-stigma and increasing help seeking behaviours.

Keywords: Family Caregiver, Stress, COVID-19, Help-Seeking Behaviors

The Coronavirus Disease 2019 (COVID-19) is defined as an extreme health hazard, economic as well as a social emergency. It was declared a global health pandemic by the World Health Organization in the March of 2020 (World Health Organization,

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2020). This novel virus mainly causes respiratory and digestive tract symptoms, ranging from mild self-limited disease to extreme levels such as severe pneumonia, acute respiratory distress syndrome and more so, even systemic multiple organ failure syndromes (Sun et al., 2020). Lockdowns and life restrictions were imposed worldwide in an attempt to prevent and slow down the spread of the virus. Developing countries were especially hit hard because of the unavailability of medicines, oxygen, and adequate resources to cater to such a large population.

Common experiences such as the fear of coming in contact with the virus and/or an infected person, the frustration related to the inadequacies in basic supplies, the sense of confusion caused due to the inadequate quality of information from public health systems and government authorities, sense of isolation, as well as the frustration and boredom due to a loss of an individual's usual routine with significantly reduced social interactions were also identified to be major causes of distress in the population. (Brooks et al., 2020). Currently, the pandemic does not fit into prevailing criteria for traumatic events yet, however, emerging pathogenic event models mainly focus on people's past experiences of certain kinds of life-threatening events which affected how they perceived the pandemic (Bridgland, et al., 2021). In view of these findings, researchers have made several efforts to better explore the possible psychological impact of the ongoing COVID-19 global outbreak, while also developing and validating the specific tools needed to measure the same (Sun et al., 2020).

Increased Stress and Burden on Family Caregivers

When the second wave hit India in April 2021 (Bogam et al., 2021), there was an acute shortage of hospital beds and resources which led to patients being cared for at home even with chronic symptoms or being discharged early from the hospitals to accommodate new patients. Family members became the sole caregivers to the patients during this time. Research conducted on caregiver burden reflects that family caregivers are oftentimes biologically and psychologically affected resulting in damage caused by the patient care process. Caregivers also face reduced jobs, social interactions, bonding time with family and friends and are further exposed to certain physical and psychological stressors that lead to caregiving overload and emotional exhaustion.

Research showed that a variety of positive as well as negative experiences were experienced when family caregivers had to move into their caregiving roles for certain members of their family. Several factors have been associated with caregiver distress which include being isolated, reduced personal leisure time, lack in knowledge, age of the caregiver, lack of support and help from other members of the family, and moreover, guilt over ignoring some demands and complaints of the patient (Rahimi et. al, 2021). Some other chief stressors which have been reportedly experienced among caregivers comprises vagueness, stigma, discrimination, change in relationships with the patient and others, and compassion fatigue. On the other hand, having hopeful feelings about themselves, compassion, satisfaction, acquiring new skill sets, and strengthening familial bonds are some of the positive and optimistic experiences indicated by family caregivers. A study found that caregivers in the age bracket of 18-30 years experienced that caring for critically ill patients had resulted in making them stronger and much more responsible, thus, providing them with a sense of growth (Rahimi et. al, 2021). Cutrino and colleagues (2013) found that caregivers who perceive a lack of social support and a high burden of caring for their relatives may be in need of additional support.

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Self-Stigma as a Barrier to Seeking Help

Self-stigma is the internalization of the existing public stigma, which results in lowered self-esteem and self-worth in individuals (Clement et al., 2015; Vogel et al., 2013). This model of internalised stigma of seeking help indicates that the more someone thinks people equate stigma with seeking help, the more stigma they will experience. Research has stated that internalized stigma is a mediator in a pathway from public stigma to negative help-seeking avoidance (Mackenzie et al., 2019; Vogel et al., 2013).

Help seeking becomes essential when the pandemic affects the psychological well-being of people, especially in family caregivers who are burdened with additional responsibilities. However, the implications that this virus has may increase psychological barriers which ultimately decrease an individual's willingness and ability to actively reach out for help from professionals due to feelings of stigma and shame (Reynders et al., 2014).

The Department of Psychiatry at the University of Leipzig, reported in the study that at the core of help seeking intentions among the population lies the belief that seeking help for a problem related to your mental health is actually helpful. (Schomerus & Angermeyer, 2008) COVID-19 and its repercussions actually increase the psychological barriers leading to unwillingness and inability to actively reach out for help from professionals commonly due to the attached stigma and shame (Girolamo, et al., 2020). Corrigan and colleagues (2012) found that internalised stigma was the primary barrier to help-seeking caused by the fear of others' judgment (Corrigan et al., 2012). Thus, it is essential that studies explore SSOSH in greater depth so initiatives can be made to create awareness; decrease perceptions of stigma for at-risk populations; and promote timely help-seeking (Jennings et al., 2015).

Current Study

The gap in the literature so far reflects that there is not an adequate amount of research or studies conducted on family caregiving, especially in developing countries that is conducted with male participants. Another gap identified is that very little research has been conducted on an exploration of stress/traumatic experiences while caring for family patients suffering from coronavirus since the pandemic is so recent. Thus, the present research aims to explore and understand the caregiver burden and the stigma attached in help-seeking among family caregivers of COVID-19 patients. The study will explore additional factors like socioeconomic status, death of a loved one, lack of family or community support and if they impact the mental health of the caregiver further. Moreover, this study intends to use a larger sample.

METHODOLOGY

Aim: The present study aims to understand the impact of SSOSH on the perceived stress of family caregivers of COVID-19 patients.

Objectives

- To study the relationship between self-stigma of seeking help and perceived stress.
- To study the impact of self-stigma of seeking help on perceived stress.
- To explore lived experiences of family caregivers of COVID-19 patients.

Study participants

The study was conducted on caregivers of family members infected with COVID-19. All participants were above 18 years of age and were taken from different parts of India using

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purposive sampling. For the quantitative and qualitative phases of the study, data were collected from 89 and 12 participants respectively.

Study Design

The study was conducted using a Mixed-methods research design. A qualitative phase followed the quantitative phase of the study.

Tools

- ***Sociodemographic details-*** Socio-demographic data of the sample was collected. This included their general information regarding their age, sex, marital status, family structure, caregiving setting, clinical information of COVID-infected family members, and if they experienced loss during their caregiving experience.
- ***Perceived Stress Questionnaire-*** It is a 30-item questionnaire that assesses stressful life events and the sleep quality of an individual. The scale requires 10-15 mins of the respondent's time for completion. It has an internal consistency ranging from .90 to .92 with test-retest reliability of .82 (Levenstein et al., 1993).
- ***Self-Stigma of Seeking Help (SSOSH) scale-*** The scale has 10 items that measure self-stigma of psychological help-seeking. The scale's reliability is .91 with good content, criterion, and predictive validity (Vogel, Wade, & Haake, 2006).
- ***Semi-structured interview schedule-*** In-depth interviews were conducted with the participants (based upon a semi-structured interview guide). The interview questions were reviewed by multiple researchers to provide their subjective judgment on set criteria.

Procedure

For the purpose of the study, participants were contacted using purposive sampling and were then familiarised with the study. Informed consent was taken from each individual using google forms to ensure complete confidentiality and acknowledgment of the risks and benefits of participation. Afterward, sociodemographic details were taken from the participants followed by the administration of the Perceived Stress Questionnaire and SSOSH scale. For the qualitative phase of the study, interviews were conducted via video calls. The interview began with a discussion on safety guidelines and then questions related to the participant's life experiences, the existence of any self-destructive thoughts and behaviors, or any history of trauma were asked. Interviews were recorded (purely for transcription purposes) after informing and gaining consent from the participants. Finally, all the data that was collected was analyzed and the appropriate interpretations were recorded.

Data Analysis

The study was conducted in two phases. For the quantitative phase, data were analyzed using the SPSS version 28.1.05. Apart from carrying out descriptive statistics, correlation and linear regression were also carried out to draw inferences from the empirical data. For this study, P-value < 0.05 was considered significant.

Thematic analysis was carried out for the qualitative phase. After obtaining the necessary consent, the individuals were approached and interviewed. Themes raised across participants were collected, and the overarching themes that offered more general insights into caregivers' experiences as a whole were identified. For the purpose of avoiding any

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inconsistencies in the interpretation and crafting a coherent story, each author independently reviewed this study.

RESULTS

89 participants (n=89; 49 females, 39 males and one individual who preferred to not disclose their sex) took part in the study. Their age ranged from 18 to 72 years with a mean age of 39 years (SD=14.73). 16.85% participants reported experiencing loss during caregiving for COVID-19 patients. 73 participants were caretakers in home isolation settings, 4 reported being caregivers to family members hospitalized and 12 reported giving care in both settings to family members. 41.5% of participants reported having experience as a caregiver pre-COVID. 70.78% of participants looked after family members with prior co-morbidities. The mean score of SSOSH was 19.39, and the mean transformed score of perceived stress was 0.48.

44.94% of the participants reported higher perceived stress scores (Transformed score>0.50). 37.07% participants showed higher SSOSH scores (Calculated score>20). Females reported a higher mean perceived stress score (mean =0.55) compared to males (mean=0.40). However, SSOSH mean score was found to be higher with male participants (mean= 19.79) than female participants (mean= 18.83).

Quantitative Results

Table 1 Correlation between SSOSH and Perceived Stress

| | | SSOSH | PSQ |
|--------------|---------------------|-------|-------|
| SSOSH | Pearson Correlation | 1 | .218* |
| | Sig. (2-tailed) | | .040 |
| | N | 89 | 89 |
| PSQ | Pearson Correlation | .218* | 1 |
| | Sig. (2-tailed) | .040 | |
| | N | 89 | 89 |

*. Correlation is significant at the 0.05 level (2-tailed).

There is a significant positive relationship between SSOSH and perceived stress in family caregivers of COVID-19 patients (r-value = .218).

Table 2 Regression analysis table of SSOSH predicting Perceived Stress

| R Square | Beta Co-efficient | B | F | p |
|----------|-------------------|------|-------|-------|
| .048 | .218 | .361 | 4.351 | 0.000 |

4.8% of the change in perceived stress could be predicted by SSOSH with statistical significance. Beta-coefficient for SSOSH is 0.006. Thus, the regression model (PS=0.361+0.006*SSOSH) suggests that for every 1 unit increase in SSOSH, perceived stress will increase by 0.006 units.

Qualitative Results

The main aim of the present study was to understand the impact of SSOSH on perceived stress among family caregivers during COVID-19 pandemic. The following section focuses on the various themes that came across through the qualitative phase of the study.

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Psychological Impact

The psychological impact of caregiving can be significant, particularly for those who are caring for patients with Covid19. The impact on mental health has been spanned across two sub-themes- *Mental health distress and Dysfunctionality*. Participants reported experiencing mental health distress through varied levels of stress and anxiety. Participants also experienced feelings of helplessness, guilt, isolation, and fear resulting from several factors related to caregiving and the Covid19 situation. Dysfunctionality was reported resulting majorly from physical distancing and social isolation. Participants shared about decreased levels of daily functioning due to the physical and emotional demands of caring for a family member, fear and uncertainty of dealing with a novel virus, feeling of being cut off from the outside world and unable to care for their own needs.

Physical Distress

The process of caregiving had a significant impact on the physical health of the family caregivers as they dealt with the physical demands of round-the-clock caregiving. The participants reported experiencing physical strain on their bodies, feeling of being exhausted, sleeplessness, negative impact on the appetite and weight-related issues. Some participants also reported the mental and emotional distress manifesting through physical distress, for instance lethargy, irritability, and gut-related sensations.

Psychological Impact (Post-covid)

Participants reported that post-covid, there were significant emotional changes. There were positive as well as negative psychological impacts. For some participants, the caregiving experience brought in a sense of achievement and a feeling of pride, as they were able to help their loved ones. They also reported that there was a huge sense of relief knowing that the difficult phase had come to an end. Participants shared that they started enjoying little moments of happiness and expressed gratitude towards it. However, for the majority of the participants, the experience of caregiving negatively impacted their mental health post covid. Participants shared that the process brought in a lot of anxiety and fear due to uncertainty. They became more cautious and worried if they or their family members would contract the virus again. They also reported feeling more cranky and emotionally unstable post the caregiving process.

Behavioural Changes (Post-covid)

The caregiving experience brought in positive and negative changes in the participants' behaviour towards themselves and/ or other people. Several participants reported that they felt like making their health a priority and became more conscious about their eating and sleeping patterns. They felt motivated to exercise and indulge in self-care. Participants shared that they are more proactive and now make sure to stay in touch with their loved ones. On the other hand, few participants also reported that the caregiving process impacted them negatively. They noticed a decline in their social interactions, energy, and productivity levels. They also indicated having sleeplessness and lethargy.

Coping and Social Support

The participants reported that as a result of their experience, they now have certain coping mechanisms they employ to handle stressors tied to COVID-19. Some of these include preparing for crises, avoiding negative news stories or social media posts, taking things day by day, and remaining upbeat despite adversity. To manage the stress associated with caring, many self-care and physical activities (drawing, baking, cooking, writing, getting enough

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rest and nourishment, yoga, and meditation techniques) were used both during and after the experience. However, several participants mentioned developing harmful coping mechanisms as a result of their stressful experiences, such as binge-watching television, binge eating, excessive sleeping, and overworking. Several participants concluded that their experience caring for a family member infected with the virus resulted in personal growth, resilience, and an increased appreciation for life. They stopped taking the little things in life for granted; they concentrated more on their health; and they developed stronger relationships with loved ones.

One of the main strategies used by the participants to deal with the burden of caring for their family members throughout the pandemic was social support. Participants reported that being checked on by their family, friends, and neighbours helped them feel at ease and cared for. Many people reported receiving food, medications, and groceries from others in their social circles. Video calls, getting together with loved ones to watch movies or play games, or even learning new instruments and skills, have all been highlighted as effective methods for reducing stress. However, participants said that unwanted advice and suggestions, sharing of unpleasant information and messages, as well as frequent fights and disputes brought on by isolating with family members, caused more anguish.

Help Seeking stigma

Some of the participants talked about the importance of seeking help during the interviews, especially when required. However, overall, the results reflected an underlying stigma involved and hesitation to accept that help was needed. The participants talked about 'seeking help' as purely curative and not a preventative measure to cope better. Other participants showed keen interest to go for therapy but were stopped by other people's biases.

They were keen to seek help which could be due to recent importance that mental health has been receiving in the media and news. Especially after COVID-19, people have become more aware and vocal about their own struggles or advocated the struggles of someone they lost due to poor mental health. However, even after talking so much about the importance of mental health, most individuals have underlying biases and believe stereotypes about seeking help. As a result, seeking help might be cheered in public but looked down upon, internally. None of the participants of the study were seeking professional support when the interviews were conducted. Very few reportedly sought help prior to their caregiving experience. The self-stigma towards seeking help and stereotypes attached to it seemed to act as an obstacle.

DISCUSSION

During the COVID-19 pandemic, the caregiver's function is crucial to the health and wellbeing of the patient, hence it is important to address any unwanted negative effects on caregivers.

Key objectives of this study were to study the correlation between perceived stress and SSOSH; to establish the impact of SSOSH on perceived stress; and to explore the lived experiences of stress and stigma among family COVID-19 caregivers. In investigating certain socio-demographic details of the participants of the study, it was found that females reported higher perceived stress when compared to the male sample. Both of these outputs were supported by previous literature in different populations (Chirico & Khamisani, 2022;

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Graves et al., 2021; Harutyunyan et al., 2020; Ondokuz Mayıs University & Topkaya, 2014). A research study in 2019 concluded that higher self-compassion was a protective factor for self-stigma of seeking help level in men (Booth et al., 2019).

The results of the first two objectives suggest that SSOSH and PS have a significant positive relationship (r -value = .218); with SSOSH predicting 4.8% of the impact on perceived stress among family carers of COVID-19 patients. Similar findings were reported in a study that evaluated stress, depression and anxiety symptoms in parents of children infected with the coronavirus (Orsini et al., 2021). Another study found that caregivers of dementia patients had a general reluctance to seek help with some of the barriers being lack of access to appropriate information, stress associated with caregiving and experiences of stigma (Messina et al., 2022). These conclusions have implications for identifying caregivers who, as a result of feeling more stress than usual, may be at risk for giving care that is of lower quality.

With the qualitative interviews with 12 participants, the objective was to explore the lived experiences of family caregivers of COVID-19 patients. Five main themes were obtained, including 'psychological impact', 'physical distress', 'post covid experiences', 'coping and social support', and 'help-seeking stigma'. The findings from the qualitative data suggest that a family caregiver's experience includes the impact of the caring process on their psychological health (leading to varied levels of mental health distress and dysfunctionality), physical health (varied levels and symptoms of physical distress), and significantly affects their lives post the caregiving process. The major changes post-caregiving were at the emotional and behavioural levels of the participants. The positive changes, such as a sense of relief and gratitude for recovering from the disease, and a motivation to follow healthier and meaningful lifestyles, stemmed from the uncertainty that surrounds the COVID-19 virus and how it has challenged the mere vitality of our lives. The negative long-term impact among caregivers reported emotional instability, continued physical strain, and reduced productivity due to the extreme caregiver burden and fatigue, along with deprioritized self-care for the caregivers themselves. The high burden on the family caregivers of COVID-19 patients can significantly threaten their mental health, an alarming proposition for mental health policymakers and professionals (Mirzaei et al., 2020).

The participants reported using various coping mechanisms to deal with the stressors of the caregiving process. Self-care activities, managing exposure to negative information spread by the media, and keeping an optimistic outlook were a few of them. However, one of the most important protective factors reported by many of the participants was social support, which particularly helped them to manage their caregiver burden. Many participants shared that talking to their friends and extended family members over a video call was a great stress reliever for that period. The relationship between social support and enhanced caregiving quality has been extensively established by research findings (Rahimi et al., 2021; Schulz, 2016; Otis-Green and Juarez, 2012).

Seeking assistance becomes crucial when the pandemic affects people's psychological well-being, especially caregivers who are faced with increased stressors and its long-term impact. However, seeking professional mental health support has been for years and is still faced with several impediments, with the primary being stigma attached to mental health. Among the 12 participants, three of them reported going for professional therapy prior to the pandemic for other personal concerns. Every participant agreed that seeking mental health

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support is important and is the need of the hour, but none of them sought therapy to deal with the caregiving stress. Reasons behind this shared by participants included that "they could manage their problems on their own", "talking to friends and family helps resolve all issues". These factors can often be a barrier to getting the help that is needed. There were certain individuals who readily agreed that seeking help is important and has its own benefits, and they either took it or looked forward to it. Professional mental health support can offer much-needed relief, providing a space for caregivers to process their feelings and develop coping strategies. In addition, professionals can offer valuable resources and advice on how to navigate the challenges of caregiving during a pandemic.

CONCLUSION

Overall, more than half of the participants of the study reported perceived stress, females more so than males. Most participants reported psychological impact and physical distress post COVID-19, as well as during the caregiving process. However, many participants also reported positive coping mechanisms and behavioral changes to reduce stress during the process. Although some participants discussed the need for help-seeking i.e. professional support, none of them were seeking help at the time, thus reflecting the need to enhance awareness of professional support when it comes to mental health, and normalizing the same. The study thus reflects that caregivers have experienced tremendous change, both positive and negative, through the caregiving process during the ongoing pandemic in India.

Limitations and Future Considerations

The current study helps to bridge a gap in the literature, especially research conducted post COVID in the Indian cultural context to understand help-seeking behaviors and the impact at large in caregivers of COVID patients. A huge population around the globe were caregivers due to shortage in hospitals, hence this study would greatly benefit their current wellbeing by bringing to light the need for more intervention models for their psychological and physical health. However, even though the current study revealed significant findings about caregivers' perception of self-stigma and help-seeking behaviors post their experience of caregiving for someone during COVID, the study has certain limitations. The sample size for the study is low because of the difficulty in approaching participants due to the sensitive nature of the study. The loss to follow-up resulted in several participants who dropped out of the study and chose to not give an interview. This added to the low sample size. Also, since continuous scales were used, it was difficult to categorize the data. Another limitation of this study was the lack of quality research on this area. Covid-19 is still a new phenomenon and although research is being conducted about all its aspects over the years, the research question of the current study is still largely unexplored.

Future studies can implement longitudinal work to further understand the impact of COVID-19 in-depth. Also, help-seeking behaviors and the loss variable can also be assessed further for more in-depth findings. Future studies may focus on the effectiveness of interventions that lessen the self-stigma of seeking professional or peer support in reducing the psychological distress of caregivers.

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Conflict of Interest

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