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Exploring the Mental Health of Caregivers of COVID-19 Patients: A Qualitative Study

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Abstract

A large body of assessment literature suggests that the caregiver of any patient goes through distress while taking care of the patient. Recently, the pandemic due to the Coronavirus called for a lot of family members to act as caregivers. The situation was even more mentally taxing as the disease is communicable, has no specific cure and the country is facing shortage of medical supplies to further deal with it. A purposive sample of seven people filled in an online survey with open-ended questions and shared their experiences of caregiving. The obtained data was analyzed through thematic analysis. The different themes gathered highlighted the phases through which the caregiver's mental health went. The caregivers felt mentally exhausted, lost and fearful for their patient's condition but their faith in God and constant efforts towards the patient's health kept them going.

Keywords: caregivers, mental health, Covid-19, stress, burden

Introduction

The caregivers need to understand the patient as a whole, as an individual with needs and preferences. Understanding a patient's medical personality might include whether or not they need special dietary restrictions or preferences, what their financial situation is, whether or not they need reliable transportation, in what language they converse most easily, and several other personal and social issues about them.

As per World Health Organization, Covid-19 is an infectious disease caused by a newly discovered Coronavirus. The virus that causes it is mainly transmitted through droplets

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generated whenever an infected person coughs, sneezes, or exhales. One can be infected by breathing in the virus if he/she is within close proximity of someone who has COVID-19, or by touching a contaminated surface and then their eyes, nose or mouth.

Recently, the pandemic due to the Coronavirus called for a lot of family members to act as caregivers. The situation was even more mentally taxing as the disease is communicable, has no specific cure and the country is facing shortage of medical supplies to further deal with it.

It is tough to give your time and take care of a patient. Initially, the caregivers are quite calm and sign up for all sorts of responsibilities but slowly and gradually people tend to experience burnout and may ultimately give up. Unawareness of the illness (Physical, Mental or Emotional) and reduction of empathy may lead to the emergence of such negativity. Feeling exhausted every night when going to bed, having more things to do than one can handle, not having time for oneself and finally getting accustomed to a routine but then the patient needs change, maybe some of the negative aspects of caregiving. The difficulties all include Financial, Emotional and Physical. The caregiver may themselves develop health-related and sleep problems, anxiety, low energy or exhaustion limits, breathing problems etc. However, giving your time, patience and care to a patient out of love for them is what keeps the caregiver going. Often knowing that if you would have been in the patient's place they would have not thought twice before doing the same for you.

In case of the patient being an elder or parent figure. The life of the caregiver takes a full circle. They reminisce about how their parents took care of them when they were younger, no matter what the circumstance was and also try to give their little one's life lessons expecting them to be there for them when they grow up and face similar situations.

The caregiver tries to spend as much time as possible obtaining more knowledge from the patient and also tends to grow closer to the care recipient. Through the caregiving process, the caregiver becomes more confident about his/her abilities and learns how to deal with difficult situations. Lastly, the satisfaction that the caregiver receives when the recipient is well cared for is also a very important aspect.

Theoretical Perspective or Conceptual framework

The Caregiver Stress Theory (CST) has been derived from the Roy Adaptation Model. It helps understand the relationship between caregiver and the patient. According to the Caregiver Stress Theory a caregiver’s stress is mostly based on factors like the objective burden in caregiving, other stressful life events, demographic characteristics, social roles and social support. The focus is on how the caregiver perceives, responds and adapts to environmental change around themselves.

As per the Caregiver Stress Theory, input of stress happens through focal stimuli, contextual stimuli and residual stimuli. Focal stimuli comprise of the major tasks associated with caregiving on the patient. Contextual stimuli are the stress of life events, social roles and social support. Lastly, residual stimuli include demographic characteristics- gender, age, type of relationship etc. The output are the adaptive modes like physiological, self-esteem, mastery of caregiving abilities, role function and interdependence.

The theory predicts that depression is the initial and most readily aroused outcome of caregiver stress. This theory helps understand what are the factors that lead to caregiver stress and what a caregiver can effectively do to adapt themselves to the stress they face.

The burden that caregivers face can also be viewed through the Transactional Model (Lazarus and Folkman, 1981). According to the model, caregivers deal with stressful situations through appraisal of stressors and resources. The primary appraisal is focused on the individual

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meaning of interpretation of the stressors, that is, specifically on taking care of the patient. The secondary appraisal tries to analyse the resources available and understand the capabilities of the caregiver. To see how one can adapt and cope with the stressful situation. The stress or burden may arise from the 'imbalance' between the demands (primary appraisal) and resources to cope (secondary appraisal). Thus, the pressure and stressors overpower the caregiver's perceived ability to cope.

Review of Literature

Rosland et al. (2021) conducted a cross-sectional online survey to compare the family caregivers with non-caregivers on physical, psychosocial, and financial well-being outcomes during the Covid-19 pandemic in order to determine family caregivers are most at risk for adverse outcomes. The results were consistent with caregiver stress-health process models and reported that the family caregivers face increased burden, duties, adverse health, negative physical, psycho-social and financial outcomes. The implications proposed the need to increase support to the caregiver during such times (Kazmi et al., 2020; Sharma et al., 2021).

With respect to care and support for the caregiver, a study by Alessi et al. (2021) aimed to understand the psychological impact of the Covid-19 pandemic on the guardians of children and adolescents who were diagnosed with type 1 diabetes with the help of an online survey. As per the results concern, burden and mental health disorders are likely to be present in the mentioned caregivers and behavioural alterations are expected to further enhance the situation as the daily challenges and can put a heavy psychological strain on those responsible for the patient.

In order to investigate the perceived additional burden by the informal caregivers during the Covid-19 pandemic in Germany, Budnick et al. (2021) conducted a cross-sectional survey with the help of questionnaire which assessed Covid-19-specific changes in the care situation,

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measures, concerns/excessive demands, loss of support, change in informal caregivers' own involvement in care and problems with provision etc. With the help of binomial and multiple regression analysis these issues were related to five indicators of care involvement, namely, being the main caregiver, high expenditure of time, high level of care, dementia, and no professional help. No significant associations were found with the involvement indicators for aspects like provision, negative feelings, change in the care situation, gender etc.

Wang et al. (2020), explored the psychology of nurses caring for Covid-19 patients using the phenomenological approach through face-to-face or telephonic interviews. The results summarized the sample's psychological experience into four themes-negative emotions, self-coping styles, growth under pressure and positive emotions. The positive and negative emotions were intertwined and existed simultaneously. During the initial stage the negative emotions were dominant but the positive emotions slowly and gradually made their way through. The nurses were able to adapt and cope with the situation through self-coping styles and psychological growth.

The negative mental health of distressed caregivers often leaves an impact on several relationships that the caregiver shares with others around. Russell et al. (2020) used path analysis to examine concurrent patterns of parents' experience due to initial challenges of caregiving during Covid-19. The results indicate a strong association between parents' caregiver burden, mental health, and perceptions of children's stress. Further these linkages are significantly related to child-parent closeness and conflict, indicating chances of spillover effects for parents diagnosed with depression and compensatory effects for anxious parents.

Studies highlight how the biopsychosocial challenges arising out of the Covid-19 virus are harmful not only for the elderly but also the caregivers of the elderly. The provisions have resulted in additional caregiver burden and stress. A review article by Anand et al. (2020)

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focused on how the pandemic should be viewed as an opportunity to initiate a paradigm shift in multidisciplinary elderly care in the country, India. Also, technological support which has been developed to alleviate caregiver burden can possibly be sustained as a significant component of elderly care.

Aim of the study

The purpose of this research was to explore the experiences of caregivers of Covid-19 patients to understand what changes their mental health went through. It aimed to understand what were the thoughts that occupied the caregivers' minds during that time and what were the mechanisms or strategies that acted as motivators and helped them overcome the situation.

Significance of the study

The findings of this study may help others gauge an insight into what phases a caregiver goes through. The pandemic situation i.e., Covid-19 has led to a change in the need and understanding of people concerning mental health. It is important to understand that not just the patient but also the needs of the caregivers should be looked into. This study tries to propagate how the burden and load they are carrying can be divided and the mental health of the caregiver should also be prioritized and respected.

Method

Research Design

An exploratory descriptive study was carried out using online survey questionnaires. The research study is qualitative in nature.

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Sample

The sample size consisted of seven respondents (two males and four females). The method used to identify the participants was purposive sampling technique. Indian residents above 18 years, who had been caregivers to at least one Covid-19 patient, were enrolled for the study.

Data collection

The survey questions were constructed by the researcher on the basis of the theoretical framework and attained review of literature. The questions were open-ended in nature. The survey was floated online through Google forms. The form was used for the participants to elaborate on their experience as caregivers to Covid patient/s.

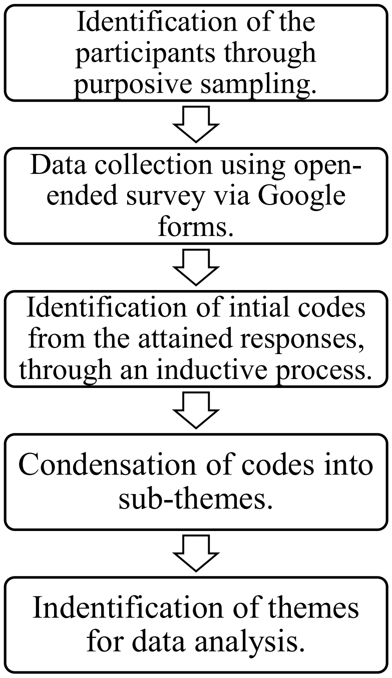
The questionnaire was structured and self-made by the author. The questionnaire guided the flow of questions moving from introductory questions onto tapping the negative and then positive feelings which the caregiver experienced. The positive questions were serially placed later so that they could leave the respondent with the satisfaction and happiness that the tough times have passed and there were mechanisms that helped through the rough phase. Each question of the survey tried to incorporate a description of the purpose of the research. To ensure the validity of the survey all the questions were reviewed multiple times and checked for accuracy.

Data analysis

The data collected through survey was utilized to identify initial codes through an inductive procedure. The attained codes were further condensed into sub-themes. Lastly, through the process of thematic analysis, the final themes were arrived at and analyzed with reference to the responses.

Figure 1

Methodology depicted through a flow-chart



Ethical Considerations

Informed consent of the participants was taken, they were informed what the research study was about and what it aimed to explore. Not only were the participants' participation voluntary but they could also withdraw their response from the study at any given moment of time.

Lastly, as the study might be emotionally triggering for participants, the researcher had made sure the participants could reach out to her or seek professional help (email address of professional help was provided).

Results and Findings

With the use of thematic analysis some common themes emerged out of the obtained responses. The results help us explore not only the mental health of the caregivers but also gives us a sneak into their physical health too.

Themes

Mental exhaustion and fear

All the respondents expressed that they often felt lost and tired. Most of them feared what if things further went downhill. There were constant negative thoughts, a sense of tiredness and restlessness that persisted.

Long recovery period

It is seen that during the first wave of Coronavirus, patients expressed less severe symptoms and recovered timely. But exceptions are always there and the second wave saw just the opposite of the initial one. Higher numbers of respondents observed a greater amount of time being taken for their patient's health to show any progress. The road to recovery being longer can mostly be attributed to comorbidities like diabetes, stronger virus strain and older age group. A positive correlation can be seen between the deteriorating mental health of the caregiver and time period taken for the patient's recovery.

Additional stressors

Though most respondents had no other thought except their patient's well-being on their mind. Some did have thought about balancing education, cooking, cleaning and other commitments creeping into their minds and acting as added stressors.

No help from others

Some respondents also lacked support from other family members and found themselves in a state of helplessness. They felt that solely managing everything took a toll on their mental and physical health due to the increasing burden of responsibilities.

Low physical and mental strength

Since, some of the respondents were either unwell or had just recovered from Covid-19 themselves they had lower physical and mental strength to cope with the situation at hand.

Instillment of Hope

Even though the times were hard for each respondent, none of them lost hope. Each respondent had their moments of weakness and all kinds of negative thoughts coming to their mind but they did not succumb to them. Unfortunately, four patients out of seven were also admitted into the hospital but the caregivers made sure of channeling emotional support and strength to their patients even during such a time.

Disrupted eating and sleeping schedule

None of the caregivers had a healthy eating and sleeping schedule. Since the disease requires constant monitoring of Oxygen (SpO2) levels, dosage of medicines, steroids and insulin and measurement of sugar levels etc., all the caregivers went through disrupted sleep schedules, untimely sleeping and eating habits as well as loss of appetite and sleep.

Faith in God

As per the responses one of the strongest motivations for the caregivers was their faith in God that helped them overcome this calamity. They indulged in chanting, repeating or listening to religious songs (bhajans, mantras etc.) themselves and making the patients hear them too.

Love and respect for the patient

Each caregiver delightfully answered that it was nothing but their love and respect for their caregiver that kept them going. There was nothing that mattered to them above and beyond their patient's health and happiness.

No fear of self-catching the virus

Despite the Coronavirus (Covid-19) being a communicable disease, none of the caregivers developed the fear or anxiety of catching it. On the other hand, for most of the respondents the actual concern was some other family member- especially someone who was more vulnerable (e.g., someone with Diabetes) falling prey to it. Each caregiver, although cautious, still overlooked the fact how they could be affected by the virus themselves and face symptoms for at least fourteen days.

Constant attention towards the patient

On an average it is seen that in the early time period of being Covid positive the symptoms of the patients are at their utmost and then slowly and steadily as the steroids and medicines are administered the symptoms subside and the patient moves towards the road to recovery. As per the caregivers not only when the symptoms were at their peak but also when they started to subside, the caregiver's constant attention did not divert from their patient. The caregivers had tasks which required constant devotion to the needs of the patient. Checking oxygen levels, giving insulin, measuring sugar levels and body temperatures, to name a few.

Motivational factors

The caregivers mentioned a few motivational factors that helped them through this difficult time. Most responses included phone and video calls with friends and loved ones, listening to music to calm themselves down, their pets, and as mentioned earlier their faith in God.

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Negative news around

Anxiety was often provoked due to all the negative news that surrounded the caregivers. As per the Statistics there was a high death rate in the country and many people were admitted into the hospitals, such that it was difficult to find a vacant bed at the hospitals. The shortage of the required medicines, oxygen cylinders and hospital beds led the caregiver to be overcrowded by harsh thoughts of what will happen if their patient's condition deteriorates and they are unable to make the required arrangements.

Limitations

One of the limitations may be that the online questionnaire sent out was self-constructed by the researcher. It does not necessarily pass all stages of good reliability and validity.

The sample population comprised seven people in total with an unequal standing of males (two) and females (four). A larger sample would have led to better transferability or generalizability of results.

Lastly, the sample method opted for purposive sampling which is highly prone to researcher's bias as the judgement of sampling are not on the basis of any expert elicitation or theoretical framework but merely on the basis of convenience.

Discussion

With reference to the theoretical frameworks the themes attained can be explained and understood well. In accordance with the Caregiver Stress Theory, the stress that most respondents faced was on the basis of the burden which was mainly associated with the patient's condition and the other stressors related to caregiving. Social roles and social support could also be seen as playing a very important role but it was majorly how the caregiver chose to respond and adapt towards the differing environment around them that helped them succeed. A hierarchy could be seen among the input of stress for the caregivers. The focal stimuli being

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the most important, contextual stimuli falling behind it and residual stimuli being the least important.

Also, the responses fell in line with the Transactional Model. How the caregivers dealt with the stressful situation was based on the appraisal of stressors and resources. The caregivers fully interpreted the stressors on a primary basis and then their capabilities and available resources to fight back the situation and take care of their patient.

Conclusion

The different themes gathered highlighted the phases through which the caregiver's mental health went. The caregivers felt mentally exhausted, lost and fearful for their patient's condition but their faith in God and constant efforts towards the patient's health kept them going.

The stress that caregivers go through should be given the right kind of importance. A solo caregiver is likely to suffer and might also develop mental and physical issues themselves due to the burnout they face. It is necessary that work is divided well among a few caregivers if possible so that the burden can be shared.

As per the information collected, a social support system, pet/s, music, undying love and respect for the patient and faith in God act as good motivators and also help the caregivers strive through the difficult times.

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