

Original Research Article

The effect of COVID-19 pandemic on quality of life of family caregivers of chronically ill patients, health expenditure and home-based medical devices in India: a cross sectional study

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Received: 15 May 2023

Revised: 07 June 2023

Accepted: 07 July 2023

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ABSTRACT

Background: The novel coronavirus had a severe impact on India, with cases ranging from mild disease to severe multiple-organ failure syndrome. Caregivers of high-risk individuals face additional responsibilities that have detrimental effects on their mental and physical health. This study aimed to assess the quality of life of family caregivers, the impact on health expenditure, and the role of home-based medical devices during the pandemic in India.

Methods: This retrospective study collected data from 358 participants using a validated caregiver self-assessment questionnaire and demographic details. The data were processed using the statistical tool chi-square, with p-value <0.05 considered significant, and analyzed using SPSS 11. The data is depicted using pie charts and bar diagrams.

Results: 93.02% of our participants assumed a caregiver role. Among these, 58.26% reported mental distress. 7.21% of caregivers reported using telemedicine facilities, and 32% reported an increase in health-related expenditure in an attempt to provide better medical care to their loved one. More than 80% of the participants reported having a family member suffering from diabetes, while 70% reported old age or hypertension. Less than 10% had a loved one who was a pregnant woman or a frontline worker.

Conclusions: The study highlights the significant impact of the COVID-19 pandemic on the mental health of family caregivers of chronically ill patients in India. The use of telemedicine facilities and the increase in health-related expenditure reflect the need for advancement in healthcare infrastructure in India.

Keywords: Detrimental effects, Health expenditure, Multiple-organ failure syndrome, Telemedicine facilities

INTRODUCTION

The novel coronavirus is a rapidly spreading, highly contagious disease caused by SARS-CoV-2, an RNA virus identified in Wuhan, China. It has shown an extensive course in India, affecting thousands of people, spread by respiratory droplets and presenting with respiratory and digestive tract symptoms, ranging from mild self-limiting disease to severe pneumonia, acute

respiratory distress syndrome and multi-organ failure syndrome. Children, the elderly and people with immunocompromised states such as pregnancy, diabetes, chronic lung and respiratory disorders, cardiovascular disease and HIV are at a higher risk of infection, hence developing severe disease. This results in higher morbidity in these high-risk groups.¹ Family caregivers have a crucial role in supporting and maintaining functionality, especially during such times. Common

consequences of restriction indoors are emotional irritability, lethargy, self-medication errors and apprehension to visit the hospital for special care.² As the coronavirus pandemic is rapidly sweeping across the world, it is inducing a considerable degree of fear, worry and concern in the population at large, moreover affecting certain groups such as older adults, immunocompromised individuals and care providers, both family caregivers and healthcare workers.³

Nationwide lockdown, work from home and the threat of collapse of the healthcare infrastructure have led to an increase in family responsibilities including financial burden for those suffering from COVID-19, and protection against the infection. This is concerning, especially for existing caregivers of chronically ill individuals which tends to have a detrimental impact on both mental and physical health. Studies reveal higher rates of mental distress, in the form of anxiety and stress, and there has been an obvious reduction in physical activity, respectively.⁴ Additional measures to control the spread of infection like quarantine and contact tracing have affected the lives, routines and livelihoods of the masses— levels of loneliness, depression, harmful substance abuse and self-harm or suicidal behaviour are also expected to escalate.³ Increased knowledge and understanding of the disease also increase the use of medical devices for monitoring and maintaining various health issues, in turn adding to the financial burden, and increasing the overall expenditure on healthcare.

Existing family caregivers, who have a significant amount of responsibilities- ranging from monitoring, homecare, managing finances and ensuring access to health facilities to adhering to complex medical regimens and treatment administration- and experience continuous distress regularly, should hence, be identified as a 'high-risk group for mental health concerns. This accounts for addressing the existence of mental distress in these individuals and consequently, improving awareness and access to mental health facilities.^{5,6}

In view of this existing threat, the following study has been planned for baseline assessment of the quality of life of family caregivers, the impact on the health expenditure and its role in the medical devices industry during the COVID-19 pandemic in India.

METHODS

This was a retrospective study that involved the collection of data from 358 participants throughout India via an online survey, using the 'Caregiver Self-Assessment Questionnaire' and demographic details. Those who refused to give consent were excluded. Most caregivers included family members taking care of a loved one suffering from diabetes, hypertension, old age, cardiac disease, respiratory disorders, neurological conditions, nephrology ailments, cancer, or those who had children, pregnant women or frontline workers in the family.

The Caregiver Self-Assessment Questionnaire validated the 18-item self-report scale, originally devised by the American Medical Association, was used.⁷ Ethical approval was taken from the Institutional Ethical Board.

Statistical analysis

The collected data were processed using the statistical tool chi-square, with a p-value <0.05 being considered significant and data analysis was done using SPSS 11. The data was entered in excel sheets and depicted using pie charts and bar diagrams.

RESULTS

93.02% of the people who participated in the study considered themselves to be caregivers to a relative or loved one with 'high risk' suffering from diabetes, old age, hypertension, cardiac disease, respiratory disorder, neurological conditions, serving as a frontline worker during COVID-19 pandemic, or had children, pregnant women, or patients diagnosed with cancer or nephrological ailments. 58.25% of these participants reported having mental distress. In an attempt to provide better medical care to their loved ones, 7.21% caregivers reported use of telemedicine facilities and 32% people reported an increase in health-related miscellaneous expenditure (Table 1).

Table 1: Demographics of participants.

Demographic	N (%)
Total number of participants	358
Number of participants who considered themselves as caregivers	333 (93.02)
Number of caregivers facing reported mental distress according to the questionnaire	194 (58.25)
Number of caregivers who utilized telemedicine facilities	24 (7.21)
Number of caregivers reporting an increase in health-related miscellaneous expenditure	118 (32)

More than 80% of the participants had a loved one suffering from diabetes, while 70% people had a family member suffering from old age or hypertension. 20-40% of the participants had a loved one suffering from cardiac, respiratory or neurological conditions or serving as a frontline worker during COVID-19 pandemic or children. Less than 10% participants had a loved one who was a pregnant woman, or a person suffering from cancer or nephrological conditions like chronic kidney disease. 26.12% participants reported that their loved ones suffered from multiple comorbidities, as depicted in Figure 1.

This study observed a remarkable upward trend in the purchase and use of home-based medical devices, as

depicted in Figure 2. Around 50% of participants reported the purchase of thermometers, sphygmomanometers and pulse oximeters, while more than 70% of people reported the use of these devices. 40% of people operated glucometers and 13% made use of air purifiers. An increase in health-related miscellaneous expenditure was also seen, presumably due to effective health education during the pandemic and augmented awareness of the

need for self-monitoring, telemedicine facilities and healthy lifestyles. All these factors have a direct effect on the overall health expenditure of India. In an out-of-pocket healthcare delivery system, the impact of the deteriorating mental health of caregivers with a simultaneous increase in expenditure on care, effects may be catastrophic.

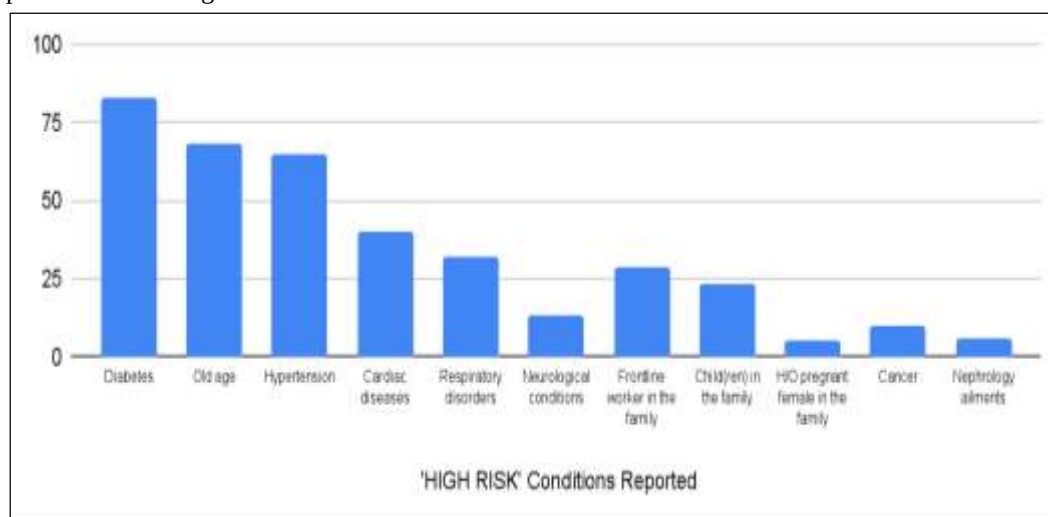


Figure 1: Common ailments reported in 'high risk' individuals.

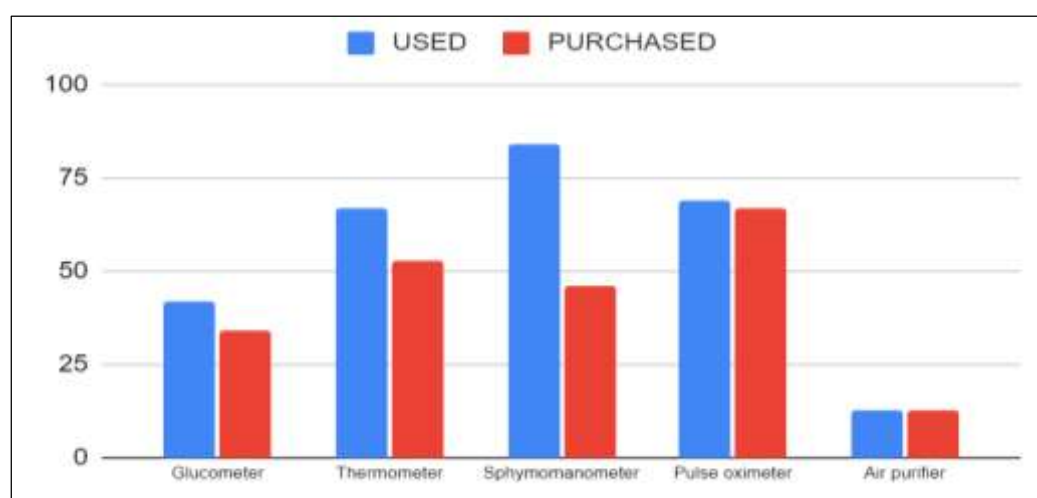


Figure 2: Trend of purchase and use of home-based medical devices.

DISCUSSION

The COVID-19 pandemic has affected thousands of people, especially threatening the lives of high-risk individuals. Consequently, protective measures required to provide satisfactory care for these groups of the population have been invariably higher and more demanding.

The execution of such care can have an overwhelming effect on both the family caregivers and healthcare workers. While several studies have been conducted to

assess the impact of COVID-19 on healthcare workers, family caregivers remain an overlooked group. Our study took into consideration non-medical professionals practicing as caregivers, those responsible for following prescribed treatment while ensuring the individual needs and demands of the patient are being met. Due to the extensive course of treatment and care for the chronically ill, caregivers often face exhaustion. Additionally, family caregivers usually have a heightened sense of responsibility, probably owing to financing simultaneously being involved in providing care. This is a reason for mental distress, making caregivers prone to mental health issues.

According to a systematic review of 117 worldwide researches, 40% of healthcare workers were found to have anxiety while 38% were diagnosed with depression, with 31% suffering from an acute stress disorder and 29% in a state of burnout. This is strikingly similar to our findings of about 58% of family caregivers reporting mental distress. Alarming, more than half of the participants in our study reported having trouble coping with the task at hand. This indicates the need for intervention to alleviate the quality of life of family caregivers.

The present study presented significant findings on the impact of COVID-19 on family caregivers in India, but had certain limitations. The sample size was relatively small and limited to a specific geographic region, which may not be representative of the broader population. Additionally, the study relied on self-reported data, which could introduce bias and limit the reliability of the results. In future research, larger and more diverse samples could be used to improve the generalizability of the findings. Using objective measures of caregiver burden and mental health could also provide more reliable and accurate data. Further, it could also provide a platform to identify and intervene in the target population.

CONCLUSION

This study highlights the dire impact of the COVID-19 pandemic on the mental health of family caregivers in India. As a rather overlooked group, these individuals suffer from mental distress attributed to caregiving. This highlights the pressing need to address the psychological effects and provide appropriate interventions. While the use of telemedicine facilities and home-based medical devices shows promise in improving access to healthcare services and reducing the burden on caregivers, the cost of healthcare remains a significant challenge, especially for families from low and middle income countries. Thus, it is critical for policymakers to prioritize the development of affordable and accessible healthcare services for high-risk individuals and their caregivers. Future research should focus on investigating the long-term effects of the pandemic on the physical and mental

health of caregivers and developing interventions to alleviate these effects.

Funding: No funding sources

Conflict of interest: None declared

Ethical approval: The study was approved by the Institutional Ethics Committee

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Cite this article as: Gupta U, Khurana S, Sampagar A. The effect of COVID-19 pandemic on quality of life of family caregivers of chronically ill patients, health expenditure and home-based medical devices in India: a cross sectional study. *Int J Community Med Public Health* 2023;10:2827-30.