

REVIEW ARTICLE

The Burden of the Stroke Caregivers in the Covid-19 Pandemic: A Short Review

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ABSTRACT

Stroke is the third leading cause of adult disability and mortality in Malaysia. During the COVID-19 pandemic, delivering care to many stroke survivors may lead to poorer caregivers' mental and physical health. The social burden among stroke caregivers may be compromised when the social connection in a pandemic is limited. This review article discusses how the COVID-19 pandemic has had a significant impact on stroke caregivers' lives in terms of various burden (e.g., physical, psychological, developmental, social), with time demand intersected in these aspects. The roles of sociodemographic factors and social connection in contributing to these burden were also discussed. A conceptual framework which illustrates the interrelationships between various sociodemographic variables and different aspects of social connections, and their links to caregivers' burden (especially in relation to the COVID-19 pandemic) was put forward for future empirical investigations.

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INTRODUCTION

Stroke is the most common cause of adult impairment and dependency, putting a strain on individuals, families, and healthcare resources (1). Stroke survivors necessitating the assistance of informal caregivers, (i.e., family members, relatives, friends, or neighbours) (2,3). The coronavirus disease 2019 (COVID-19) outbreak contributed to an increase in mortality rates and affecting the healthcare system worldwide (4–6). About 2000 stroke survivors and their caregivers have been affected in every aspect of stroke services during the pandemic (7,8). Disruptions of access to stroke rehabilitation services were reported to increase caregivers' burden (9–11). Standard operating procedures like travel restrictions, stay-at-home rules, and no-visitor policies make caregivers worry about their stroke-affected family members even more (12–14), making it harder for them to give stroke survivors the appropriate care.

METHOD

This article searched peer-reviewed publications in

English using EBSCOHost databases and narrowed the search results from Medline Complete, Springer Nature Journal, Psychology and Behavioural Science Collections for a period of 5 years on October 5, 2023, using a combination of search terms including "stroke caregivers burden" AND "social support" AND "social isolation" OR "loneliness" AND "pandemic COVID-19" AND "sociodemographic" OR "socioeconomic status". This search strategy yield 573 non-duplicated articles. Additional hand-searching of article bibliographies was also undertaken.

Twenty seven articles were selected based on the selection criteria that describe caregivers' burden of stroke patients during the pandemic, including factors such as sociodemographic and social connection. As this was a short review, we limited our screening to the article title, abstract, and conclusion for each term evaluated. Author MFR was responsible for the data extraction, which was then reviewed by all three co-authors (PLC, SLC, and SR) independently. This article review aims to answer the following research questions: 1) What are the impacts of the COVID-19 pandemic on stroke caregivers' burden (i.e., physical, psychological, developmental, social, and time)? and 2) How do factors such as age, marital status, socioeconomic status (SES), and social connection (i.e., social support, loneliness and social isolation) contribute to the burden?

RESULTS

Eight articles were extracted based on the selection criteria as a final result. Main findings of the evidence pertaining to stroke caregivers' burden and its impact during the COVID-19 pandemic is summarised in Table 1.

COVID-19 Impacts Caregivers' Lives

Informal stroke caregivers who perform therapeutic tasks for the stroke-care recipients are commonly described as efficient and cost-effective (15,16) but they often receive limited training (10,17), which could result in poor recovery outcomes for stroke-care recipients (18). The COVID-19 pandemic, with measures like a no-visitor policy and therapy cancellations in stroke rehabilitation facilities, has resulted in stroke survivors becoming increasingly reliant on their caregivers. This has escalated the physical and psychological strain on caregivers (12,15,19,20). In Italy, 27.9% of stroke patients stopped receiving rehabilitation treatments because they had no other options to deliver care in the initial phase of the pandemic (10,21). However, little is known about the additional burden placed on informal caregivers due to this restriction to healthcare access (10,22).

Stroke caregivers experienced poorer physical health than the general population after delivering care (13,14,23). The level of diverse strain experienced by them is referred to as caregivers' physical burden (19). About 55% of stroke caregivers reported feeling burdened in some way, with the majority reporting physical and mental stress (24). During the COVID-19 pandemic, stroke caregivers' physical health is declining after longer hours of care without physical help from formal rehabilitation staff (25,26).

Although tele-rehabilitation was adopted in some

countries using a multi-disciplinary formal care approach such as occupational therapy, physiotherapy, speech therapy, and nursing, this approach ironically added more physical stress on caregivers due to the additional tasks needed when preparing an online session (5). This could be due to the fact that some caregivers fully relied on the therapist for formal care delivery before the pandemic. Caregivers were worried that switching to online services and treatments would make it harder for them to deliver the appropriate care due to additional tasks required in an online rehabilitation service (27). This would make their physical load heavier during the pandemic (28).

Interrupted formal care services can also heighten the physical burden, especially during the initial phase of delivering care to stroke survivors (25,28). Hence, research has recommended to include the informal caregivers to facilitate the treatment regime (29). The hospital authorities should consider improving the caregiver-therapist network during the pandemic to avoid delayed care for stroke survivors (10,30). Thus, involving caregivers with rehabilitation therapists while maintaining frequent contact helps caregivers to be physically competent while delivering care.

A psychological burden is when a person is overwhelmed and emotionally drained while delivering care. Induced stress while delivering care to stroke patients could lead to physical or verbal abuse (13,25). A previous research has reported a high risk of emotional distress among informal caregivers (11). A meta-analysis study found that depression and anxiety add to the distress of being a stroke caregiver (31).

During the COVID-19 pandemic, Movement Control Orders (MCO) were initiated by the Malaysian government in March 2020 to restrict people from

Table 1: Stroke caregivers' burden during COVID-19 pandemic

Study	Findings
Lee et al. (2021) (25) & Sutter-Leve et al. (2021) (10)	Providing extended care to stroke patients without the assistance of formal rehabilitation personnel will increase the burden on caregivers and reduce support.
Utisang et al. (2021) (46)	The obligation of providing full-time care to family members incentivises stroke caregivers to offer unforeseen support.
Pelicioni et al. (2020) (12)	The interruption of formal care among stroke survivors increases caregivers' physical and psychological burdens.
Baricich et al. (2020) (20)	COVID-19 pandemic, no visitor policy and therapy cancellation obstructed care for stroke survivors, further increasing the caregivers' burden.
Bailey et al. (2022) (28)	Informal caregivers have higher physical burden.
Hado & Feinberg, 2020 (52)	Spouses of stroke survivors felt some degree of burden, especially in family and social relationships, and financially.
Ashghali et al. 2021 (38)	Supportive home environment decreases the stroke caregivers' burden.

travelling and help mitigating human-to-human virus transmission (32). Although restricted, caregivers are still able to socialise when they commute for their daily essential activities such as buying groceries, seeking medical attention, and/or working as frontliners, but performing these activities may posit some psychological distress (13,33,34).

Additionally, their concerns about potentially transmitting the virus to stroke patients and the fear of being blamed by other family members might collectively contribute to many caregivers' hesitance to participate in social activities during the pandemic lockdown (23,35). Simultaneously, stroke caregivers were more likely to feel anxious and depressed because of the fear of getting infected and spreading the virus to the already vulnerable stroke care recipients (36). Caregivers including those caring for stroke patients have faced increased demands during the pandemic, which has led to increased levels of stress, anxiety, and depression (11). The additional workload such as sanitation activity to avoid virus transmission among caregivers and their care recipients continue to increase caregivers' psychological burden (22), and not beneficial to the patients' mental health outcomes in the long run (22–24). Therefore, distress related to the pandemic may be linked to worse psychological well-being and eventually posit a higher psychological burden.

Perceived feelings of missing out on life and personal life burden are examples of developmental burden among caregivers (37–39). When family caregivers drastically change their future plans due to prolonged hours of care and commitment, and commonly unprepared to continue delivering basic tasks to meet the patients' needs after discharge, they eventually experience a developmental burden throughout their caregiving phases for stroke patients (31,39). It has been reported that stroke caregivers missed out on life 3 months after the post-stroke period (39,40). An increase in weekly care hours of caregivers is also linked to stroke-related symptoms and severity in patients (15). Gertrude et al. (2019) found that when caregivers spend their free time doing caregiving tasks, they tend to ignore their own health and well-being (38,39,41). Given that stroke patients have the highest recovery rate within the first 3 months from the stroke onset (42–44), the developmental burden in caregivers during this critical recovery period for stroke survivors can be particularly high (45). During the pandemic, the developmental burden among stroke caregivers remained unknown when COVID-19 has had a different burden of its own. Despite the burden, some caregivers expressed gratitude for the opportunity to provide unanticipated support for their family stroke survivors during the pandemic (45,46). However, when caregivers must adjust to the new COVID-19 norms, this may increase their developmental burden and risk of poor health, and the prolonged pandemic situations would not help in the long run (3,45).

Conflicts with other family members about care decisions and feelings of isolation are examples of social burden (47,48). Other family members who do not appreciate the efforts in providing care for stroke patients enhance caregivers' feelings of burden. Behar-Zusman et al. (2020) found that family conflict and cohesion are important stress-related factors that can either increase or decrease the psychological effects of COVID-19 on adults (47,49). It is clear that this is also true for caregivers' families. During a pandemic, informal caregivers were unable to share their physical and developmental burden with other family members who are residing in different locations following the travel restrictions (12,30). Meanwhile, interactions with family members can help to mitigate the psychological effects of major stressors (49). Therefore, the long hours of caregiving during a pandemic add to the social burden on caregivers during this hard time.

Sociodemographics Factors and Burden in the COVID-19 Pandemic

The severity and consequences of COVID-19 depend on a patient's age, with most adults over 65 being hospitalised and at a higher risk of death than those under 65 (50). Excessively worried about COVID-19 can hinder older family caregivers' ability to care for morbid patients at home (11,14,48) including stroke survivors. Additionally, COVID-19 affects older people more than younger people because of their increased comorbidities and psychosocial burden (50,51). Elder caregivers may live with more fear of contracting an infection and affecting their daily roles as well as their general health (3,30,52). Although younger caregivers were also affected by the COVID-19 pandemic, their fear of contracting the disease is lower than that of older caregivers (50). Individuals with comorbidities such as diabetes, cardiovascular diseases, and hypertension may have severe consequences in both young and older people (53). However, the elderly caregivers, who sustained multiple chronic health complications, may be worried even more about delivering appropriate care during the COVID-19 period.

A study showed that the majority of the caregivers who were the spouses of stroke survivors felt some degree of burden, especially in family and social relationships, and financially (23,52). Caring for a stroke spouse and providing family support is crucial because feeling inadequate at managing households and providing care at the same time increases stress, eroding the marriage relationship (17,50). Moreover, spouses who are caring for hospitalised chronic stroke patients should get additional care, especially when they are having poor health condition and financial difficulties (31,45). Meanwhile, evidence has shown that with psychoeducation, elderly spouse caregivers experienced decreased stress over time and showed improvement in caregiving competency (31). This indicates that the prevalence of depression and anxiety among caregivers

can be helped with psychological support. How far this would help during the COVID-19 pandemic remains unknown.

Family caregivers were unpaid, and their efforts to provide care were not without cost (16,54). Socioeconomic status (SES) refers to social status or class whereby education, income, and occupation are frequently used to measure it. Higher education, which is also commonly associated with higher SES, is related to better physical health among stroke caregivers (26,41,55). Zhu and Jiang (2018) found that occupation status had minor to moderate effects on their caregivers' burden (19,56). Nonetheless, numerous scholars anticipate that the economic instability stemming from the COVID-19 pandemic will be considerably more severe and have a disproportionate impact on racial minorities, single-parent households, and families with low SES (49,57). Moreover, female stroke caregivers, with less education and unemployed, have low SES and carry a significant burden (58).

According to the National Health and Morbidity Survey (NHMS; 2019) (59), caregivers with higher SES (particularly those with higher education levels) could afford private services and this reduced the interruptions to their caregiving roles and household chores (60). However, during the COVID-19 situation, to what extent this privilege has helped the burden among higher-income caregivers remains unknown. Since the travel restrictions applied to all groups of people regardless of their SES, stroke caregivers from various backgrounds might be equally affected by the caregiving burden.

Financial support is necessary to improve the health of caregivers and care recipients (61). A study estimated that the yearly caregiving cost is higher in the United States compared to Malaysia (62). However, the stroke caregiving costs are expected to increase in Malaysia following an increase in stroke incidence over a five-year period (16,63). It is assumed that this may further increase the economic burden among Malaysian caregivers during a pandemic. The costs of caregiving for post-stroke patients remained scarce during the COVID-19 pandemic. Since caregivers have to buy their own protective equipment, this adds to their financial problems (19,25,64).

Social Connection and Caregivers

Social connections and relationships with others are essential for enhancing the quality of life required for human survival. Caregivers who experience loneliness may endure emotional distress, which in turn can impact their biological defense mechanisms (14,65–67). Prior to the COVID-19 outbreak, loneliness and social isolation were prevalent across all age groups in America, and the pandemic has disrupted numerous traditional avenues for social connection. (68–70). The challenges associated with social connectivity are exacerbated by

the COVID-19 pandemic, leading to a consequential impact on the health of caregivers (71). Hence, it is crucial to explore the connection between social connections and caregivers' burden by considering dimensions such as social support, loneliness, and social isolation.

Stroke caregivers require social support to alleviate the burden of caregiving. (38,72,73). They normally seek support from the local community, including relatives, neighbours, and household members (74). Liu et al. (2022) established the importance of social support in enhancing the quality of life within the context of stroke caregiving. (64,75). A meta-analysis showed that social support significantly predicted an individual's health, indicating a clear relationship between better social support and lower disease and mortality rates (76). A decreased social support among stroke caregivers may result in a diminished capacity to share their burden with others (38,77), hence correlated with poorer mental health (75,78). The study also revealed that within the group of untrained caregivers, women were more likely than men to feel obligated to provide care for the family's requirements at the expense of their own, and consequently, they received less social support. (78,79). Amidst the pandemic, the importance of social support from healthcare providers has become increasingly evident. To alleviate the social burden on caregivers, it has been recommended that healthcare facilities offer psychoeducation programmes to enhance the caregiving skills of stroke caregivers (26,80). Stroke caregivers who received support increased by seven percent in 2020–2021 as opposed to the pre-pandemic situation (81), emphasising the crucial role of social support during a pandemic. In Malaysia, efforts were made to maintain COVID-19-free conditions within the stroke rehabilitation units. COVID-19 patients, including those in recovery from stroke, were strictly prohibited from entering, leaving the current status of COVID-19's impact on social support for stroke caregivers in Malaysia uncertain (82). Although receiving social support does not predict stroke caregivers' adjustment towards their caregiving role (73), social disconnection which leads to poor social support is a crucial determinant of poor health (12,83).

Stroke caregivers may overlook their social requirements in their lives and exchange them with caregiving tasks, ultimately leading them to social isolation and loneliness (71). The high caregiving intensity levels of a spouse prevented stroke caregivers from socialising with their friends (84). Engaging in social and recreational activities is correlated with increased well-being among caregivers, whereas a decrease in daily activity involvement is correlated with feelings of social isolation and loneliness among caregivers. (66,84,85).

Amidst a pandemic, the risk of social isolation and loneliness affects everyone. Elderly caregivers, who are already at a heightened risk, have experienced

unexpected separation from their social circles due to illness or the loss of a spouse or partner(67). A study reported that one out of every four people aged > 65 is socially isolated, and approximately 43% of adults aged > 60 have reported feeling lonely during the COVID-19 pandemic (65,86). Grieving, when shared with family and friends, can provide significant support after a loss. However, COVID-19-induced social isolation has limited the chance for the support network from both family and the community (87,88). Stroke caregivers who are already prone to psychological pressures as a result of their caregiving duty may face a lengthier period of grieving (71,88). This could have added to the level of loneliness for caregivers, particularly the elderly, during the pandemic. Findings suggest a link between social isolation and loneliness to higher risks of poor physical and mental health, including high blood pressure, heart disease, obesity, a weakened immune system, mood and anxiety disorders (66,88).

On the other hand, the increase in the number of online activities during COVID-19 allows caregivers to connect with others. Online classes for cooking, crafts, and faith-based organisations that offer streaming services, including online study groups and special events, have been found to deepen their caregivers' spirituality and increase connectedness (72). However, there is limited studies exploring the influence of online activities on the social burden of caregivers .

CONCLUSION

In summary, caregiving burden in the aftermath of pandemic stress was evidently influenced by their social connections and sociodemographic factors. . The dynamic of these interrelationships can be seen in Fig. 1, which illustrates the different aspects sociodemographics (such as age, SES, hours of care, and marital status) and their relationships with caregiving burden. On the other hand, social connection (i.e., social isolation, loneliness, and social support) also contributes to the development or progression of stroke caregivers' burden, which can be further divided into different aspects (i.e., developmental, physical, emotional, social, and time demands). Additional research using empirical data from the COVID-19 pandemic should be conducted to examine this proposed framework.

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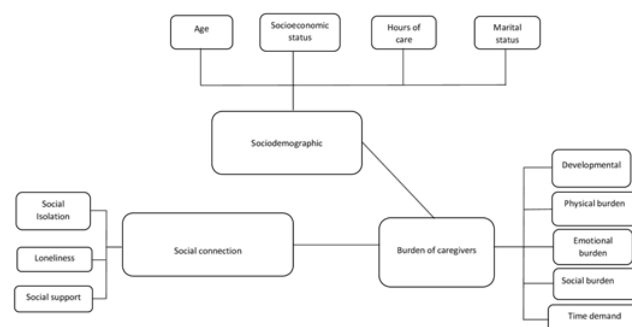


Figure 1: Illustration of the different aspects of sociodemographic factors (age, socioeconomic status, hours of care and marital status), social connection (social isolation, loneliness, and social support), and their links to the burden of caregivers (developmental, physical, emotional, social, and time demands).

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