

Stroke survivor caregivers face barriers to accessing care for themselves, study finds

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Caregivers of stroke survivors are facing some challenges accessing support for themselves, according to a new study. Credit: Vlada Karpovich/Pexels

When planning ongoing care for a stroke patient, the focus tends to rest on the patient with sometimes little consideration for the family member or friend who will be their caregiver.

Now, a new study is shining a spotlight on the challenges faced by [stroke](#) survivor caregivers when accessing health and [social services](#) for

themselves.

Led by Arthur Labatt Family School of Nursing professor Anna Garnett and published in *BMC Health Services Research*, the study highlighted some significant barriers caregivers face when accessing support. These barriers include financial factors, lack of transportation, and lack of awareness about available services.

The study emphasized the need for Canadian policymakers to acknowledge and understand the challenges caregivers face to develop programs that support stroke survivor caregivers in a more meaningful way.

"There is a need to consider [caregiver](#) access to services," said Garnett. "And it's not just about providing the service but also ensuring they are able to use it."

Caregivers in the study were not only subjected to reduced income or termination of their employment so they could provide care; they are also facing the loss of the stroke patient's income if the patient was a primary earner in their family, the study said.

Even when there were financial subsidies and [support programs](#) intended to assist them, caregivers are often unaware or uninformed about what is available and whom to contact for more information.

The study suggests greater connectivity and communication between health-care providers, community programs and social services would increase ease of access and usage. Developing roles, such as stroke navigators, who can assist caregivers in managing their options for assistance, would also help address accessibility concerns.

Caregivers in the study also described being left behind or forgotten by

their friend groups and social networks.

"In some cases, they felt invisible," said Garnett. "While they received inquiries about the wellness of their charge, their own needs did not garner similar attention and concern. Reduced [social support](#) meant that caregivers had even less assistance with basic tasks and needed respite services to manage their household."

Accessing respite services sometimes proved to be fraught with additional challenges for caregivers, the study found. They noted difficulty developing trust with health service providers who care for the stroke survivor, due to issues with changing personnel and unreliable service.

When unsure of who would be caring for their charge, caregivers were less likely to leave home to address their own needs. Similarly, when faced with the potential of leaving the stroke survivor alone, caregivers were less likely to leave, feeling anxious about the possibility of another stroke while they are away.

The findings from the study highlight the need for readily available, affordable and accessible health and social services, Garnett said.

"Including caregivers within the circle of care for stroke survivors—along with health providers, [social workers](#), and program providers—would likely increase service accessibility," she said.

"Fostering trust between caregivers and health providers through increased, ongoing engagement would enable opportunities for better responding to caregiver [health](#) and social service needs."

More information: Anna Garnett et al, Factors impacting the access and use of formal health and social services by caregivers of stroke survivors: an interpretive description study, *BMC Health Services*

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