

Caregiver stress: The crucial, often unrecognized byproduct of chronic disease

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There is growing evidence that caregivers of patients with cardiovascular



disease (CVD) are vulnerable to developing their own poor cardiovascular health. Investigators report in the *Canadian Journal of Cardiology*, published by Elsevier, on a proof-of-concept couples-based intervention in a cardiac rehabilitation setting. This intervention has shown potential for reducing caregiver distress, and future studies are evaluating its impact on both caregivers' and patients' cardiovascular health.

Nearly half of Canadians have been in caregiving roles to family and friends, with similar figures in the United States and Europe. A caregiver is broadly defined as someone who provides informal or unpaid work to a family member or friend with a chronic condition or disability. Caregivers provide crucial, rarely remunerated support to sick family members or friends. About 40 per cent of caregivers, of whom more than half are women, report high psychological, emotional, physical, social, and financial stresses imposed by the caregiving role. These factors can contribute to a higher risk of CVD among caregivers themselves. However, despite an appreciation of these issues, few approaches have been effective in reducing caregiver stress. This need is expected to rise in the next decade as the population ages, length of hospital stays decline, and CVD and associated risk factors continue to increase.

"It is abundantly clear that caregivers need to be better supported!" said lead investigator Heather Tulloch, Ph.D., Division of Cardiac Prevention and Rehabilitation, University of Ottawa Heart Institute (UOHI), and University of Ottawa, Ottawa, ON, Canada. First author, Karen Bouchard, Ph.D., postdoctoral fellow in behavioral medicine at UOHI added, "Caregivers are critical for patients' cardiovascular health management and are an invaluable healthcare resource, contributing enormously to the Canadian healthcare system. Individuals who care for their partners may experience additional cardiovascular risk—a risk that



should be recognized and to which we should respond."

In this narrative review, investigators look at evidence from the fields of health psychology and relationship science and highlight the direct (e.g., physiological) and indirect (e.g., behavioral, emotional) factors that link caregiver distress with caregivers' own cardiovascular risk. For example, caregivers are more likely to continue to smoke and less likely to be physically active than individuals who provide no or low levels of care; their diets tend to be high in saturated fat intake leading to greater body mass indexes; they spend less time engaging in self-care activities and report poor preventive health behaviors; they experience less or disordered sleep; and demonstrate poor adherence to medication. Spousal caregivers have higher levels of depressive symptoms, physical and financial burden, relationship strain, and lower levels of positive psychological wellbeing compared to adult children caregivers, for example.

The researchers report that the risk of hypertension and metabolic syndrome may be directly related to high-intensity caregiving, defined as providing more than 14 hours of caregiving per week over two consecutive years. They also report findings that estimate the economic contribution of caregivers' unpaid labor to be \$26 billion annually in Canada, which is projected to increase to \$128 billion by 2035 (likely translating to over a trillion dollars each in the USA and Europe).

The investigators contend that the cardiovascular health of both patient and caregiver could be improved by enhancing the quality of the patient-caregiver relationship. They describe a proof of concept testing of Healing Hearts Together, a relationship-enhancement and educational program for patients and partners. Based on attachment theory, which states that close emotional bonds are essential when faced with a threat such as a cardiac event, the program guides couples through conversations in which they review information on heart health and



attachment; share their unique experiences with heart disease with partners and peers; and learn to clearly communicate their need for connection and reassurance. This connection enhances couple satisfaction and problem solving. Participants reported improvements in relationship quality, mental health, and select quality of life measures. A controlled evaluation of the impact of the program on cardiovascular risk factors is underway.

"The aim of Healing Hearts Together is to increase emotional accessibility and responsiveness in couples facing CVD," explained Dr. Tulloch. "Taken together, couples-based interventions in a cardiac rehabilitation setting may be a timely and appropriate approach to reduce caregiver distress and enhance caregivers' comprehensive health outcomes. There is an emerging opportunity to care for those who care for their partners and enhance the health of both. It is important that healthcare professionals recognize the burden of caregiving and act sensitively and strategically to address these challenges."

"Detrimental effects of the caregiving experience are greater among middle-aged caregivers, those known as the 'sandwich generation,' because they balance paid work commitments and interpersonal relationships with care delivery tasks for parents, children, and/or partners," commented Monica Parry, NP-Adult, MEd, MSc, Ph.D., University of Toronto, Toronto, ON, Canada, in an accompanying editorial. She points out that men and women deal differently with caregiving and, as the landscape of heart disease in women is changing, so must our approach and understanding of the caregiving experiences of men. For example, male caregivers may struggle with the societal views of caring; feel invisible at times; and may be unsure how to assimilate the caring role, masculinity, and accessing help for themselves. "We are facing an epidemic of caregiver burden. Caregivers cannot remain underresearched, under-diagnosed, under-treated and/or under-supported," she concluded.



A recent <u>policy statement</u> from the American Heart Association/American Stroke Association on palliative care for CVD and stroke recommended attention to the physical, emotional, spiritual, and psychological distress of the patient's family and care system.

More information: Karen Bouchard et al, Reducing Caregiver Distress and Cardiovascular Risk: A Focus on Caregiver-Patient Relationship Quality, *Canadian Journal of Cardiology* (2019). DOI: 10.1016/j.cjca.2019.05.007

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