Canadian Journal of Cardiology 35 (2019) 1267–1269

Editorial

Caregiver Burden and Cardiovascular Disease: Can We Afford to Keep the Health of Caregivers in Canada Invisible?

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See article by Bouchard et al., pages 1409–1411 of this issue.

Nearly one-half (46%) of Canadians have been in caregiving roles to family members or friends; 50% of these caregivers are between the ages of 45 to 65 years, and the majority (54%) are women.[1] 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.[2] Caregiving roles typically include transportation, housework, house maintenance and outdoor work, scheduling and coordinating appointments, managing finances, helping with medical treatments, and providing personal care.[1] Caregiving has enormous benefits to the care recipient and the health care system. Despite these benefits, caregiving has detrimental effects on one's ability to exercise, consume a healthy diet, and maintain alcohol consumption within recommended limits.[3] 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.[3] Caregiving can also lead to financial hardship for younger caregivers, with an average loss of $1.2 million in earnings (present and future) and $30,000 in out-of-pocket expenses.[3]

Caregiving and Cardiovascular Disease

Cardiovascular disease (CVD) (eg, heart failure and stroke) accounts for 9% of caregiving in Canada.[1] Poor lifestyle and the early development of chronic disease (eg, hypertension), combined with advances in medical technologies (eg, cardiac resynchronization therapy devices), contribute to an increase in the number of years lived with a disability and an epidemic of caregiver burden.[4,5] Heart failure is the "last stop for Canadians who experience a journey through CVD."[6] The health status of these individuals is complex: they have other physical and psychologic comorbidities and, as a result, high care needs. From 2007 to 2012, the number of caregivers 45 years of age and older in Canada increased from 760,000 to 4.5 million, representing an increase of 20% in just 5 years.[1] Much of the evidence to date has focused on women as caregivers for men with heart failure, lower limb amputations, and stroke, with little research examining the caregiving experience of men. In this edition of the *Canadian Journal of Cardiology*, Bouchard et al.[7] present a nonsystematic narrative review to discuss caregiver distress and cardiovascular risk with a focus on the quality of the caregiver–patient relationship. They indicate that 40% of caregivers report high caregiver burden (eg, psychologic, emotional, physical, social, and emotional) and attribute this burden to elevated stress levels due to strained caregiver–patient relationships.[7] They further suggest that caregiver stress is independently associated with a twofold increase in risks of developing coronary artery disease (95% confidence interval [CI] 1.16-3.20) and hypertension (95% CI 1.17-4.49), and a 2.64-2.55-fold increase in risk of cardiovascular mortality (95% CI 1.50-4.65) compared with caregivers who report little to no caregiving stress. In addition to the caregiving relationship, Bouchard et al.[7] suggest other risks for caregiver burden, including female gender, comorbidities (eg, anxiety and depression), limited social supports, and the effect of the caregiver activities on instrumental activities of daily living (eg, work).

Gender Gap in Caregiver Burden

There is myriad evidence on the psychologic and physical consequences of caregiving, but this evidence exists primarily in women.[8-10] There is also emerging evidence to suggest that caregiving differs for men and for women. One might postulate that the differences in caregiver outcomes might be related to not only the biologic sex of being female or male, but also the roles, identities, relationships, and institutionalized gendered ways of being a woman or a man.[11,12] For example, Glauber[13] used data (2000-2012) from the Health and Retirement study (n = 12,704) and reported that more women aged 50-65 years provided caregiving to a partner, and as men aged and left work, men and women equally provided care to their aging partners. Swinkels et al.[14] used data from the Netherlands' Older Persons and Informal Caregivers Survey (n = 1,611) and suggested that women as caregivers did not have a greater burden than male caregivers (mean age

Received for publication June 3, 2019. Accepted June 25, 2019.

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See page 1269 for disclosure information.

https://doi.org/10.1016/j.cjca.2019.06.025

73 years) when care needs, hours of care, or support were considered. In fact, hours of care did not increase caregiver burden in women, but it did in men. Women experienced greater caregiver burden when they felt that they had multitasking difficulties or financial strain. Bouchard et al.[7] consider the risk of hypertension to be directly related to high-intensity caregiving, defined as providing more than 14 hours of caregiving per week over 2 consecutive years. They report a doubling incidence of hypertension (95% CI 1.17-4.49) and suggest stress and its effect on cardiovascular reactivity and endothelial function as primary reasons. Currently, women are more likely than men to spend more than 20 hours per week on caregiving, and for some, the time invested in caregiving is equivalent to full-time work.[1,8,15] Similar results were reported by Lacey et al.,[16] who used data from the UK Household Longitudinal Study (n = 9368) and found that women (mean age 42.9 years; n = 5,363) who provided care for 3 years or more (regression coefficient 0.48, 95% CI 0.07-0.89) or repeated shorter durations of caregiving (regression coefficient 0.47, 95% CI 0.02-0.92) had more psychologic distress than non-caregiving women. They also reported that caregiving was not associated with psychologic distress in men (mean age 44.5 years; n = 4005).

A small (n = 8) qualitative study suggested that men as spousal caregivers in palliative care felt confused and unsure how the caregiving experience fit with their identity as a man. Men felt a duty to perform and feel supported and were unsure how to look after themselves while caring for a dying partner.[17] Men also felt that they could not share feelings, concerns, or frustrations with their partners because this would impair their relationships. Bouchard et al.[7] suggest that a lack of adequate supports contributes to the physical and emotional burden of caregiving, especially for women. They suggest that supportive caregiver–patient relationships could prevent caregiver distress and ultimately reduce a caregiver's CVD risk. Chiu and Lin[18] reported Taiwanese women (n = 483) to be more likely than men to have worsened cardiovascular health (eg, hypertension, lipid profiles, inflammation) when caregiving intensity increased, but others[14] reported that caregiving intensity contributed to greater caregiver burden for men only (n = 700). These results are conflicting, but what they do suggest is that caregiving differs for men and women. Men who are engaged in caregiving may need more support in understanding the perceptions of care and the caregiving experience. Caregiving appears to vary by sex, gender, and age, although this is difficult to evaluate because much of the existing evidence report outcomes only by total sample and not separately for men, women, or different age groups.[18]

Resources for Caregiver Partners

Bouchard et al.[7] argue for couples-based interventions in secondary prevention programs (eg, cardiac rehabilitation) to improve patient and caregiver health and reduce partner caregiver distress. They also suggest that physiologic (eg, endothelial dysfunction, hypertension), behavioural (eg, smoking, physical inactivity, unhealthy weight), and emotional factors (eg, poor relationships) contribute to caregiver distress and a subsequent increase in CVD risk. Although it is difficult to determine the comprehensiveness of this nonsystematic narrative review, a recent systematic review of heart failure dyadic self-care interventions[19] supports the results of Bouchard et al.[7]; only 12 intervention studies were published in English from 2000 to 2016 and all had methodologic limitations related to sample size, blinding, or allocation. Semistructured interviews with 16 caregivers (88% women) of individuals with heart failure identified lack of supports, relationship burden, and caregiver health as dominant themes.[20] Moreover, a meta-review of systematic reviews of qualitative studies of chronic diseases, including individuals with heart failure, suggested that caregivers' help-seeking behaviours are affected by socioeconomic status, affective state, interaction quality, and caregiving demands.[21]

A policy statement from the American Heart Association and American Stroke Association on palliative care for CVD and stroke recommended attention to the physical, emotional, spiritual, and psychologic distress of the patient and the patient's family and care system.[22] Secondary prevention programs (eg, cardiac rehabilitation) offer education, exercise, risk-factor management, and psychologic support to individuals after a myocardial infarction, percutaneous coronary intervention, or coronary artery bypass graft surgery. Despite the benefits of secondary prevention programs, challenges to program enrollment, adherence, and completion exist.[23] Couples-based interventions in secondary prevention programs could potentially increase utilization and assist caregivers through education, risk-factor management, and psychologic support. Barriers to participation (eg, caregiving demands) may best be managed through facilitated home-based or web-based programs. Recent caregiver pilot intervention studies, such as **R**ehabilitation **En**ablement in **Ch**ronic **H**eart **F**ailure (REACH-HF)[24] and Psychoeducation and Skills-Based Mobilized Intervention (Pep-Pal),[25] suggest that home-based and web-based interventions are acceptable and may improve caregiver outcomes (eg, psychologic well-being).

Conclusion

As we learn more about the evolving risks for heart disease and stroke in women, we will need to understand the sex and gendered aspects of caregiving in men. Both age and gender appear to have moderating effects on partner care. Caregiving responsibilities for women after stroke occurs throughout the life stages (eg, pregnancy and menopause), yet we know little about the caregiving experiences of young and middle-aged men. Bouchard et al.[7] have predominantly focused on the caregiving experiences of women, and this is likely due to the preponderance of women as caregivers and the evidence to date. As the landscape of heart disease in women changes, so must our approach and understanding of the caregiving experiences of men; men and women deal differently with caregiving. Bouchard et al.[7] recommend couples-based interventions in secondary prevention programs to improve caregiver health and reduce partner caregiver distress. They suggest that interventions target caregiver–patient relationships and the physiologic (eg, hypertension) and behavioural (eg, smoking, physical inactivity, unhealthy weight) factors that contribute to caregiver distress and associated increases in CVD risk. The 2018 Heart Report[26] advocates educating and empowering women, and for health care systems to keep pace with new evidence about women's cardiovascular health.

Caregivers contribute an enormous amount of unpaid invisible work to the Canadian health care system. Bouchard et al.[7] estimate the economic contribution of caregiver's unpaid labour to be $26 billion annually in Canada[7]; this figure is projected to increase to $128 billion by 2035.[27] Can we afford to keep the health of caregivers in Canada invisible? Relatively few interventions targeted to the cardiovascular health of caregivers have been developed or evaluated. Men struggle with the societal views of caring, feeling invisible at times, being unsure how to assimilate the caring role, expectations of masculinity, and accessing help for themselves. Poor lifestyle and the early development of chronic disease (eg, hypertension), combined with advances in medical technologies, are contributing to an increase in the number of years lived with a disability and an epidemic of caregiver burden.[4] There is an urgent need to make the health of the caregivers in Canada visible: Caregivers cannot remain underresearched, underdiagnosed, undertreated, or undersupported.

Disclosures

The author has no conflicts of interest to disclose.

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