Sex and Gender Issues in Dementia

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Summary

The following submission to the Senate Committee describes the fundamental importance of considering sex and gender in studying dementia in Canada. Evidence shows that there are sex differences in the prevalence and risk of dementia with this disease disproportionately affecting women worldwide. Additionally, gender differences in caregiving and access to care demonstrate that dementia is an important health issue for women. Despite these known differences, health research has failed to adequately integrate sex and gender considerations, resulting in gaps in the evidence to inform dementia care. Women’s Xchange (a women’s health research knowledge translation and exchange centre based at Women’s College Hospital) is working to improve the research that informs dementia care by enhancing the integration of sex and gender in research. Considering sex and gender issues in dementia research in Canada will better inform dementia care strategies.
Introduction

Sex and gender are fundamental issues to consider in the study of dementia in Canada. Both sex (biological factors) and gender (socio-cultural factors) shape people’s health outcomes and experiences and thus have implications for developing policies and programs to improve the health of all Canadians.\textsuperscript{1-2} Despite their crucial role, the integration of sex and gender has been uneven across the fields of health research and inclusion of sex and gender considerations has yet to be adopted as a standard research practice.\textsuperscript{3} Failure to consider these concepts hinders our knowledge about differences between men and women in terms of responses to drug therapies, symptom expression, and health-related behaviours, potentially jeopardizing patient safety and undermining efforts to deliver quality care.\textsuperscript{4} Women’s Xchange (a women’s health research knowledge translation and exchange centre based at Women’s College Hospital) is working to improve the research that informs dementia care by enhancing the integration of sex and gender in research. To support this mandate, the following evidence is submitted for the Senate Committee’s consideration of sex and gender issues related to dementia in Canada.

Evidence

Sex Issues: The prevalence of dementia is highest among women

International evidence demonstrates that there are sex differences in the prevalence of dementia. The worldwide prevalence of dementia is highest among women,\textsuperscript{5} estimated to be between 23-41\% higher for women as compared to men.\textsuperscript{6} These sex differences are contextualized by the fact that age is the biggest risk factor for dementia,\textsuperscript{7} as women make up a greater proportion of the older population\textsuperscript{8} and have longer life expectancies than men.\textsuperscript{9} The
impacts of dementia on women will become increasingly crucial to address amidst the aging of Canada’s population.8

Gender Issues: Caregiving and access to dementia care

There are also gender issues to consider in dementia. For example, gendered differences in caregiving result in gendered patterns of inequality in access to dementia care. When older women receive unpaid care in the home, they are more likely to receive care from a child or child-in-law, while men are more likely to be cared for by a spouse.10 This care is primarily performed by women (daughters/daughters-in-law and wives),11 exemplifying the persistence of a gendered division of care labour in the home.12

The gendered division of care labour has significant implications for the health and well-being of women as they are thus more likely to be the caregivers of persons with dementia. Recent findings from Ontario indicate that home caregivers experience greater distress when caring for older, sicker and more frail care recipients, and that almost half (49.2%) of all caregivers of persons with Alzheimer’s disease or other dementias report being distressed.13 Caregiving takes a physical (e.g. exhaustion, pain) and mental (e.g. depression, stress) toll on the caregiver and also has implications for caregivers’ well-being in terms of compromised paid work, financial burden, strained familial relationships, and social isolation. As home care recipients are increasingly frailer than in the past,13 home caregiving of persons with dementia represents an important and growing issue for the health and well-being of the women providing the bulk of this care.

Broader demographic and socioeconomic trends further shape the gendered implications of dementia. The vast majority of long-term care residents are older women.14 Women are more likely to enter long-term care homes than men due to a tendency to live longer as well as to live
alone in advanced old age, meaning they are less likely to have someone available to help care for them in their own homes. Additionally, given that a greater percentage of women age 65+ are low income as compared to men, older women may be less able to privately pay for home care or supportive living arrangements when unpaid caregivers are unavailable or no longer able to cope with the challenges of providing care. For older women with dementia, a lack of community-based supports and income inequality may contribute to a greater reliance on long-term care. Researching the gendered impact of dementia will thus be crucial for developing care strategies that address the health and well-being of older women residing in long-term care homes.

The Research Gap: Inadequate consideration of sex and gender in dementia research

Despite evidence pointing to substantial sex and gender issues in dementia, failure to adequately consider these issues in health research has resulted in major gaps in our knowledge of how sex and gender influence dementia risk, outcomes and treatment response. Neglect of sex and gender issues is a widespread problem across the fields of health and biomedical research. A recent study has shown that despite funding requirements to consider sex and gender issues, Canadian health research continues to suffer from this oversight. Inadequate consideration of sex and gender in research has implications for the quality of evidence to inform care. For example, women have been (and remain) underrepresented in biomedical research, and clinical trial results tend not to be reported separately for men and women. A 1998 report on a clinical trial of donepezil (one of the few treatments available for managing Alzheimer’s disease) reports only the number of women included in the sample without reporting whether or how outcomes of the trial differed for men and women. This was
a pivotal trial in the field of Alzheimer’s disease and has been cited more than 1000 times to date (as of May 24th, 2016 from the Web of Science Core Collection). Failure to consider differences in treatment outcomes for men and women perpetuates gaps in knowledge about the best care for dementia and related conditions. Additionally, given poor inclusion of older people in clinical trials, there are gaps in our knowledge about drug effects specifically among older women and men.\textsuperscript{28} To be effective and to minimize the risk of adverse events, differences in treatment outcomes for older men and women must be reported and accounted for in researching pharmacological and non-pharmacological interventions for dementia.\textsuperscript{29}

**Improving the Research: Enhancing the quality of sex and gender integration**

Consideration of sex and gender issues will improve the quality of research to inform dementia care for both women and men. A number of guidelines have been developed to promote excellence in the integration of sex and gender considerations in health research.\textsuperscript{30-33} What is missing from these tools is a set of criteria for investigators to determine how well they have addressed sex and gender issues in their studies. Assessors also require standards to evaluate how well sex and gender have been integrated in a given study, program or policy.

As one of 12 research centres comprising the Ontario Strategy for patient-oriented research Support Unit (OSSU), Women’s Xchange works with health research teams to improve the quality of sex and gender integration throughout their research projects. To assist with this, Women’s Xchange has developed the *Metrics for Sex and Gender Based Analysis*. The metrics provide guidance on how to integrate sex and gender as well as assess the quality of that integration. It is recommended that the metrics be similarly implemented in conducting research to better tailor strategies for dementia care for women and men.
The *Metrics for Sex and Gender Based Analysis* guide the user through each stage of the study process, from initial issue identification, literature review and question development (Stage 1), through to the knowledge translation (Stage 5) and participant engagement (Stage 6). At each stage, a series of questions is posed about the integration of sex and gender. For example, in Stage 1 the metrics user is asked, “Have diverse populations of men and/or women and persons of diverse sex/gender identities been engaged in identifying the research issue? Have sex/gender considerations been reviewed in the background literature? Is there an explicitly defined research question that addresses sex/gender?” These questions are accompanied by a 5-point assessment scale, from ‘poor’ to ‘outstanding’ with accompanying descriptions of what each entails, allowing for a standardized assessment of sex and gender integration.

Women’s Xchange is currently validating the metrics through a rigorous review and feedback process involving Canadian and international experts on sex and gender. We would welcome the opportunity to discuss the use of these metrics in the work undertaken by the Senate Committee on a dementia strategy.

**Conclusions**

Sex and gender are fundamental to shaping health outcomes and experiences. It is thus recommended that sex and gender be considered in dementia research in Canada. Consideration of sex and gender impacts how we understand and approach health issues – not only in terms of questions about prevalence and effective treatments, but also whether and how we acknowledge the interrelated socio-cultural factors that additionally impact health and health care. A dementia strategy should be built on research evidence that integrates sex and gender, as this information is essential to inform more equitable health outcomes, policy and health care practices. The
Senate Committee is urged to consider how integrating a sex and gender lens in studying dementia can help to reveal and address disparities in Canadian health care.
References


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