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Mental health and well-being of unpaid caregivers: a cross-sectional survey protocol

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ABSTRACT

Introduction Unpaid caregiving, care provided by family/ friends, is a public health issue of increasing importance. COVID-19 worsened the mental health conditions of unpaid caregivers, increasing substance/drug use and early development of chronic disease. The impact of the intersections of race and ethnicity, sex, age and gender along with unpaid care work and caregivers' health and well-being is unknown. The aim of this study is to describe the inequities of caregiver well-being across the intersections of race and ethnicity, sex, age and gender using a cross-sectional survey design.

Methods and analysis We are collaborating with unpaid caregivers and community organisations to recruit a non-probability sample of unpaid caregivers over 18 years of age (n=525). Recruitment will focus on a target sample of 305 South Asian, Chinese and Black people living in Canada, who represent 60% of the Canadian racial and ethnic populations. The following surveys will be combined into one survey: Participant Demographic Form, Caregiver Well-Being Index, interRAI Self-report of Carer Needs and the GENESIS (GENdEr and Sex DetermInantS of Cardiovascular Disease: From Bench to Beyond-Premature Acute Coronary Syndrome) PRAXY Questionnaire. Sample characteristics will be summarised using descriptive statistics. The scores from the Caregiver Well-Being Index will be dichotomised into fair/poor and good/excellent. A two-stage analytical strategy will be undertaken using logistic regression to model fair/ poor well-being and good/excellent well-being according to the following axes of difference set a priori: sex, race and ethnicity, gender identity, age, gender relations, gender roles and institutionalised gender. The first stage of analysis will model the main effects of each factor and in the second stage of analysis, interaction terms will be added to each model.

Ethics and dissemination The University of Toronto's Health Sciences Research Ethics Board granted approval on 9 August 2022 (protocol number: 42609). Knowledge will be disseminated in pamphlets/infographics/email listservs/newsletters and journal articles, conference presentation and public forums, social media and through the study website.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ Strong community partnerships and patient partner (ie, caregiver) engagement from study inception to dissemination of results.
⇒ Methods are rooted in appropriate and strong conceptual frameworks (intersectionality and the logic model of the Caregiver Support Framework) and are well justified and integrated.
⇒ Realistic consideration given to the challenges of maintaining statistical power while including indicators of diversity in the intersectional quantitative analyses.
⇒ Interpreters will support non-English participants in survey completion, supporting diversity and inclusivity of South Asian, Chinese and Black people living in Canada.
⇒ It may not be feasible to recruit a target sample of 305 South Asian, Chinese and Black people living in Canada despite predefined strategies recommended for intersectionality research (caregiver and community partnerships, respondent-driven sampling).

INTRODUCTION

Unpaid caregiving is a public health issue of increasing importance worldwide. Unpaid caregivers are people who provide care to family members and friends in need of support with personal care, activities of daily living and instrumental activities of daily living, without financial compensation.[1] The type of care provided is diverse and can include assistance with transportation, meal preparation and clean-up, house cleaning and maintenance, laundry, personal care, assistance with medical care tasks and legal affairs, and

managing finances.[2] In Canada, distress is twice as high for caregivers who live with the person they are caring for in the community; approximately 50% of these caregivers are spouses and 30% are adult children caring for their parents.[2] This caregiver dyad relationship is one in which the care recipient usually requires assistance with activities of daily living (eg, bathing, feeding, toileting).[3] Over 32% of caregivers in this type of dyad relationship (ie, caring for a spouse or parent) have unmet care needs, leaving them dissatisfied with life and stressed on most days.[2] Most caregivers are women 35–64 years of age.[2] Caregiving impacts one's physical and mental well-being, finances and participation in the labour market.[2] Middle-aged caregivers are particularly vulnerable, balancing the competing time pressures of unpaid caregiving with participation in the workforce.[1] Loss of earnings of $1.2 million (present and future) and $30 000 in out-of-pocket expenses for 'sandwich' generation caregivers poses financial hardships and added stressors.[4] The 'sandwich' caregivers are typically 45–55 years of age and are known to provide care to a parent who is greater than 65 years, as well as at least one child.[5] In Canada, the number of people aged 65 and over is projected to double to over 4.5 million (23.3%) by 2041[6] and as the population ages, more individuals will need caregiving support.

Unpaid caregivers are the backbone of many healthcare systems. The COVID-19 pandemic caused shortages of healthcare workers and fear of going to emergency departments, which pushed family members into primary caregiving roles for their loved ones; roles in which they lacked adequate preparation and protection.[7] When home care visits from healthcare providers were disrupted, medical and tangible tasks became the responsibility of the unpaid caregiver, increasing the burden and stress for caregivers.[8] Those affected most by increased caregiving responsibilities were racial-ethnic minority populations, individuals with a higher income, those with college and university education and individuals under 55 years of age.[9] As a result of COVID-19, 42% of unpaid caregivers in Canada increased their caring activities related to domestic tasks.[9] The Centers for Disease Control and Prevention highlighted the impact of infectious disease outbreaks on worsening mental health conditions, with increases in substance and drug use.[10] The COVID-19 pandemic, with its epidemic pattern of rapid spread, transmissibility and a case fatality rate of 2.3%, caused heightened fear and anxiety for the public.[11] The impact of large-scale quarantine measures and reduced access to care for individuals with pre-existing comorbidities contributed to an unprecedented public mental health crisis.[11] These impacts extended beyond disease resolution in past outbreaks[12]—fear, anxiety, depression and post-traumatic stress disorders developed in survivors during the 2003 severe acute respiratory syndrome (SARS) and lasted for many years.[13]

COVID-19 also appeared to impact population groups differently. Specific impacts and inequalities involve intrinsic biological factors as well as sociodemographic factors driven by social inequity that increases the incidence of COVID-19 in specific groups, while protecting others. Early evidence suggested males had higher COVID-19 mortality rates than females.[14] Tadiri et al[15] also noted the prevalence of reported COVID-19 cases varied between men and women by country. They used publicly available data to determine if sex differences in mortality between countries were related to institutionalised gender (eg, education, employment), which was measured by the United Nations Development Project's Gender Inequality Index. Results suggested institutionalised gender was not associated with sex differences in COVID-19 death rates. These results highlight several important gaps, most notably that gender is broader than education and employment (ie, institutionalised gender) and that a sex-based and gender-based analysis is not simply equal to the sum of each part.

Intersectionality and good health

Added unpaid caregiving hours combined with financial strain as a result of COVID-19 created challenges for caregivers to exercise, consume healthy diets and limit alcohol consumption.[16] Added distress and unhealthy lifestyles can lead to the early development of chronic disease (eg, hypertension), posing increased risk and potential increase in life years lived with a disability. One of the United Nations Sustainable Development Goals is to achieve good health and well-being by 2030, with a focus on ensuring healthy lives and promoting the well-being of all people at all ages.[17] Leaving no one behind, one of the cornerstones of the Sustainable Development Goals[18] challenges researchers to shift ways of thinking to better understand the complex nature of health and health inequities. Intersectionality is a way of understanding and explaining complexity in the world, in people and in human experiences.[19] Recent evidence suggests intersectionality can inform interventions for public/population health.[20 21] It focuses on the relationships and interactions in society that determine health and informs direction for policy and programme development.[18] An intersectional lens pushes us to move beyond the individual factors that affect health (eg, race and ethnicity, sex, age, gender) to one that focuses on the relationships and interactions among these factors. Global communicable disease priorities are led by the WHO Communicable Disease Surveillance and Response Systems[22] and the United Nations Sustainable Development Goals (2015–2030).[17] This research study will address five of the 17 Sustainable Development Goals: No 3—Good Health and Well-Being, No 5—Gender Equality, No 8—Decent Work and Economic Growth, No 10—Reduced Inequalities and No 17—Partnerships for the Goals,[17] because these are most impacted by unpaid caregiving.

Race and ethnicity

Racial-ethnic minority older adults are the fastest growing segment of the ageing population in Canada.[23] In the USA, unpaid caregiving is high in racial-ethnic minority

populations partially due to high levels of coresidence.[24] Caregiver well-being has been described by McDonald *et al*[25] to be profoundly affected by the caregiver dyad (ie, caregiver and care receiver relationship).

In the USA, approximately 20% of unpaid caregivers across 44 states, District of Columbia and Puerto Rico (2015–2017) reported being in fair or poor health, and most were less than 45 years of age.[26] Prior to COVID-19, almost one-quarter of Asian American and one-third of African American caregivers provided 40 hours or more of unpaid care per week.[27] There is a paucity of data on unpaid caregiver experiences of racial-ethnic minority populations in Canada. Our previous search of the published literature from 2003 (outbreak of SARS) to 16 November 2020 identified 139 papers published across 32 countries, with only 38 (27%) of these reporting race and ethnicity.[28] Thirteen (9%) of the publications were from Canada, reporting on a population that was 71% female, aged 23–69 years and 80% white. One out of five people in Canada are foreign born; the three largest racial-ethnic minorities are South Asian, Chinese and Black people—representing 60% of the Canadian racial-ethnic minority populations.[29]

Sex and gender

Sex refers to the biological attributes of being male or female (ie, chromosomes, genes, hormones, reproductive anatomy).[30] Our previous search of the published literature also indicated that the three major stressors for unpaid caregivers during COVID-19 included the unintended consequences of physical distancing (eg, isolation, loneliness), financial strain and balancing decision-making for loved ones with maintaining current public health safety practices.[31] Self-reported stress was significantly related to sex, age, education and employment during the pandemic of COVID-19. Females generally experienced more distress ($\beta=-3.62$, p=0.000) than males, and adults who stopped working reported higher distress than those who telecommuted ($\beta=-2.87$, p=0.012).[32] Being a female home maker was associated with depression (OR=1.35, 95% CI 1.12 to 1.63), anxiety (OR=1.31, 95% CI 1.11 to 1.55) and post-traumatic stress symptoms (OR=1.28, 95% CI 1.11 to 1.47).[33] Stress affects cardiovascular reactivity and endothelial function, with reported sex differences in endothelial function between males and females.[34] Bouchard *et al*[35] suggest caregiver stress is independently linked with a twofold increase in coronary artery disease risk (95% CI 1.16 to 3.20) and hypertension (95% CI 1.17 to 4.49), and a 2.55-fold to 2.64-fold increase in cardiovascular mortality risk (95% CI 1.50 to 4.65) when compared with unpaid caregivers who reported little to no caregiving stress. Early COVID-19 research suggests sex differences in the expression and activity of ACE 2, as well as altered immune responses, led to worse outcomes for males with COVID-19.[36]

Gender refers to socially constructed roles, behaviours and expression.[30] The Canadian Institutes of Health Research defines gender to include four inter-related aspects: gender identity (ie, personality traits), gender roles (ie, number of hours of housework, caregiving), gender relations (ie, marital status) and institutionalised gender (ie, income, education).[30 37] Tadiri *et al*[15] suggest gender factors affected the male:female case ratios of COVID-19 in testing due to household and childcare responsibilities and exposure to occupation. Caregiver burden varies between men and women,[38] women who provide repeat intermittent care have greater psychological distress compared with men ($\beta=0.47$, 95% CI 0.02 to 0.92).[39] In addition, women only have increased caregiver burden when they perceive financial strain or multitasking difficulties.[40] Anxiety and depression are more common in women—women cut back on sleep and men give less attention to looking for paid work to adjust for extra caregiving responsibilities.[9]

Evidence gap

Unpaid caregivers are the backbone of many healthcare systems, including the Canadian healthcare system. Prior to COVID-19, more than one in three unpaid caregivers in Canada were distressed.[41] Since COVID-19, more Canadians want to live at home as they age. However, the amount of domestic and care work has increased, especially in Canadian women who are university educated, less than 55 years of age and have annual incomes greater than $80 000.[9] Individuals born outside of Canada and racial-ethnic minority populations also report increased caregiving work. However, the impact of intersections of race and ethnicity, sex, age and gender and the impact of this added unpaid care work on caregiver's health and well-being are not known. In our rapid integrated mixed methods systematic review, only 38 (27%) of the 139 studies reported race and ethnicity.[42] This represents a significant gap in knowledge.

OBJECTIVES

The aim of this study is to describe the observed inequities in caregiver well-being across the intersections of race and ethnicity, sex, age and gender.

METHODS AND ANALYSIS

The concept of intersectionality,[43] the logic model of the Caregiver Support Framework,[44] the Strategy for Patient-Oriented Research (SPOR) Capacity Development Framework[45] and the SPOR Patient Engagement Framework[46] will be used to guide this cross-sectional survey. Understanding the causes and mechanisms that lead to health inequities in women and racial-ethnic minority populations can be improved through use of the concept of intersectionality.[47 48] As an analytical tool, intersectionality views categories of race and ethnicity, sex, age and gender as inter-related and mutually shaping one another. Intersectionality is a way of understanding and explaining complexity in the world, in people and in human experiences.[19] Recent evidence suggests intersectionality

can inform interventions for public and population health.[20 21] It focuses on the relationships and interactions in society that determine health and informs direction for policy and programme development.[18] It has been used extensively in qualitative research and recently implemented into quantitative and mixed methods research.[49] An intersectionality lens will allow us to systematically examine factors that affect the health and well-being of unpaid caregivers simultaneously. The logic model of the Caregiver Support Framework was developed for use in leading collaborative improvement plans for unpaid caregivers.[44 50] It uses an outcome-oriented approach to health service delivery for caregivers, focusing on better communication and stronger supports for caregivers. When the model was developed, only 37% of caregivers reported ever being asked about how they were doing, feeling or managing. The logic model was developed by caregivers and healthcare professionals and is intended to drive a systematic approach to identifying gaps and planning improvements for caregivers.[44 50] The International Association for Public Participation defines five levels of engagement along a spectrum that outlines the patient's impact on a decision (eg, inform, consult, involve, collaborate and empower).[51] Patient partners (ie, caregivers) have collaborated in all aspects of our phase 1 study and will continue to collaborate to describe the observed inequities in caregiver well-being across the intersections of race and ethnicity, sex, age and gender.

We used the Consensus-Based Checklist for Reporting of Survey Studies[52] when preparing this manuscript (online supplemental table 1).[53] Additionally, the Guidance for Reporting Involvement of Patients and the Public–Long Form (GRIPP 2-LF) was used to document the engagement of patient partners (ie, caregivers) (online supplemental table 2).[54] The patient partner compensation rate structure used in this study is based on the Recommendations on Patient Engagement Compensation—prepared by the SPOR Networks in Chronic Diseases and the PICHI Network[55]: each patient partner will receive a 1-year honorarium of $500 that will include compensation for engagement across all activities of the project (ie, advisory, knowledge translation and exchange activities). To manage records and promote transparency, we have registered our project on the Open Science Framework (https://doi.org/10.17605/OSF.IO/PB9TD).[56]

Sample

A non-probability sample[57] of unpaid caregivers over 18 years of age will be recruited across Canada. An unpaid caregiver is defined as a person who provides care services to an adult older than 18 years of age in need of care in the home without financial compensation.[1] Services can include assistance with transportation, meal preparation and clean-up, house cleaning and maintenance, laundry, personal care, assistance with medical care tasks and legal affairs, and managing finances. Exclusions include caregivers who are paid with money to deliver care (eg, nurse, personal support worker, physician, etc).

Unpaid caregivers will be recruited through established methods (eg, email listservs, newsletters, etc) used by our collaborators and community partners, social media (eg, Facebook, Twitter, etc) and a study website (https://unpaidcaregivers.ca/). If needed, we will use respondent-driven sampling (RDS) as it is recommended for intersectionality research.[58–60] We will begin with two initial 'seeds'; each will then recruit three additional people, who themselves will become recruiters. We will continue our recruitment 'waves' until we have reached a sample of 60% racial-ethnic minority individuals (ie, South Asian, Chinese and Black people) of the total sample through established and RDS sampling methods. Self-identifying Indigenous Peoples will not be intentionally targeted, although they will be included in the sample if they choose to participate.

Procedure and measures

Our partner organisations have agreed to alert their membership to our survey through a link to our study website containing background, eligibility criteria and unpaid caregiver videos produced by our patient partners. Interested participants will contact our project coordinator via email or a toll-free telephone number. Following appropriate ethics approval, an eligibility checklist and consent will be completed prior to survey administration. Surveys will be completed using the internet or telephone and guided by patient preference, and all survey data will be stored anonymously. Collaborators will assist as intermediaries for translation of study procedures (eg, eligibility, informed consent, survey completion) for non-English-speaking participants. A user manual will be developed for collaborators and community partners who will be involved in translating the survey for study participants. Training on survey completion will also be provided to collaborators and community partners. Survey participants will be required to pass a test that assists to distinguish humans from bot automation (CAPTCHA) and each participant will be asked in an open text format to indicate how they heard about the study. The survey has also been designed so that completion can be monitored frequently and low-quality or fraudulent responses identified quickly (eg, survey completion times, inconsistent responses, comparison of postal codes to reported locations).[61 62] Survey completion compensation will not be automated, participants will receive a $10 gift card after the survey has been screened for bot automation and fraudulent responses.[63]

Guided by intersectionality and a multifactorial conceptualisation of gender, the following surveys will be combined into one survey: Participant Demographic Form, Caregiver Well-Being Index (CWBI),[64] the interRAI Self-report of Carer Needs (SCaN)[65] and the GENESIS (GENdEr and Sex DetermInantS of Cardiovascular Disease: From Bench to Beyond-Premature Acute Coronary Syndrome) PRAXY Questionnaire.[66 67] The survey consists of 66 questions and has been pilot tested by three caregivers on the Engagement Advisory Committee and

two other community members to take approximately 30 min to complete, noting an additional 30 min may be required if translation assistance is necessary. The Participant Demographic Form captures information about age, race, first language, citizenship, immigration and income using pre-established questions taken from the GENESIS PRAXY Questionnaire,[66 67] 2022 Canadian Community Health Survey,[68] Statistics Canada[69] and the Canadian Institute for Health Information.[70] The CWBI[64] is a valid and reliable measure of caregiver well-being with a Cronbach's alpha of 0.75. It consists of four questions focusing on one concept, psychological well-being. Scores range from 0 to 8 and represent four well-being levels: excellent (score of 0, low risk), good (scores of 1–3, mild risk), fair (scores of 4–6, moderate risk) and poor (scores of 7–8, high risk). High scores (ie, 4–8) represent fair or poor well-being and have been linked to negative aspects such as financial concerns, conflict with family, inability to continue in the caregiving role, physical pain and loneliness. Low scores (ie, 0–3) represent good or excellent well-being and have been directly linked to positive aspects of life.[64] The interRAI SCaN identifies the unpaid caregiver role and quantifies how unpaid caregivers experience day-to-day life. Role attributes include the caregiver's perspective on their own health, mood, relationships, support and activities of daily living.[65] In addition, the interRAI SCaN assists caregivers to identify the services needed by the care recipient and any challenges they encounter in their role as an unpaid caregiver. The GENESIS PRAXY Questionnaire[66 67] was developed to assess gender-related variables. The intersectionality analysis will focus on four gender constructs: gender identity, gender roles, gender relations and institutionalised gender (figure 1).

Sample size

We will use caregiving intensity as a proxy for well-being as the available literature on the latter is lacking. We expect adjusted ORs between 1.8 and 2.0 for the main effects of sex (male, female) and race and ethnicity.[71] Using the estimate of 35% of Canadian caregivers reporting distress,[9] and assuming a correlation of 0.2 among factors in the models, with a two-sided alpha set at 0.05, a sample of 475 would be needed to obtain 80% power to detect an OR of 1.8. To account for missing data, we will oversample by 10%, resulting in a final sample size of 525 survey respondents. Since the sample size required to detect interactions is larger than that for main effects, we will use a p value of 0.10 to determine whether the coefficient for the interaction term is significant.[72]

Data analysis

The analysis will be undertaken by a biostatistician using SAS V.9.5 (oversight MP, CN, LP). Sample characteristics will be summarised using descriptive statistics. Missing data will be assessed and if excessive (ie, >10%), multiple imputation will be considered. Total well-being will be dichotomised into fair/poor (total score 4–8) and good/excellent (total score 0–3). A two-stage analytical strategy[72] will be undertaken using logistic regression to model fair/poor well-being and good/excellent well-being according to the following axes of difference set a priori: sex (male, female), race and ethnicity (White, People/Persons of Colour), gender identity (cis-man, cis-woman/other), age, gender relations (married/partner, widowed/separated/divorced/never married/partnered), gender roles (composite score) and institutionalised gender (composite score). Composite scores for gender roles and institutionalised gender will be calculated using methods described for the GENESIS PRAXY Questionnaire.[66] The first stage of analysis will model the main effects of each factor. Unadjusted and adjusted models will be run to determine what axes of difference are associated with fair/poor well-being and whether they are independent of each other. In the second stage of analysis, interaction terms will be added to each model based on the product of race and ethnicity (White or People/Persons of Colour) and each of the other axes of difference. Akaike's information criterion will be used to determine if the model containing the interactions provides a better fit to the data than the main effects model. A better fitting model would provide evidence that at least some of the axes of differences tested have a multiplicative effect when combined with race and ethnicity. If the model with the interaction is found to be a better fit to the data, the significance of the coefficients of each interaction term will be evaluated.

Gender Identity	Gender Roles	Gender Relations	Institutionalized Gender
Cis-Man, Cis-Woman, Trans Male/Trans Man, Trans Female/Trans Woman, Gender Queer/Gender Non-Conforming	Employment Status, Primary Earner Status, Paid Work Hours, Housework Hours, Housework Responsibility, Child Responsibilities, Taking Care of Care Recipient Hours, Occupation	Marital Status	Education, Income, Financial Support, Social Standing

Figure 1 Gender-related variables.

Patient and public involvement

One patient partner (RBel) is a coprincipal investigator and four patient partners (DG, NN, KW, WW) are coinvestigators. All patient partners are active members of the study's Engagement Advisory Committee. The Engagement Advisory Committee will oversee and approve the final survey and website. This committee will also inform and collaborate in recruitment activities, assist in interpretation of the data and codevelop and codisseminate study results. Survey results will also inform a future grant application, of which patient partners will collaborate as coinvestigators. The GRIPP 2-LF[54] has been used to document patient engagement activities and we have used the patient partner compensation rate structure described in the Recommendations on Patient Engagement Compensation—prepared by the SPOR Networks in Chronic Diseases and the PICHI Network.[55] The guiding principles of cobuild, inclusiveness, support and mutual respect underpin all patient engagement activities in this study.[46]

ETHICS AND DISSEMINATION

Ethics approval has been granted by the University of Toronto's Health Sciences Research Ethics Board (protocol number: 42609; 9 August 2022). Since the recruitment strategy is not strictly inclusive of Indigenous Peoples, community engagement with an Indigenous partnership is not part of the research plan. This is aligned with the Tri-Council Policy Statement (TCPS)–Chapter 9 (2018)[73] that specifies community engagement is not required if Indigenous participation in a research study is incidental, rather than intentionally recruited. In keeping with the TCPS–Chapter 9 (2018),[73] if there are participants who self-identify as Indigenous, the researchers will assess whether culturally appropriate assistance is required in order to facilitate interpretation of the research study. A member of the research team is Indigenous and will be available to facilitate this assessment of culturally appropriate assistance, if needed. Knowledge will be disseminated in pamphlets/infographics/email listservs/newsletters and journal articles, conference presentation and public forums, social media (eg, Facebook, Twitter, etc) and through the study website.

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