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Understanding racialised older adults' experiences of the Canadian healthcare system, and codesigning solutions: protocol for a qualitative study in nine languages

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ABSTRACT

Introduction Racialised immigrant older adults (RIOAs) in Canada have poorer self-rated health and are more likely to report chronic conditions, while they concurrently experience well-documented challenges in navigating and accessing the healthcare system. There is strong evidence that patient and caregiver engagement in their healthcare leads to improved management of chronic disease and better health outcomes. International research suggests that engagement has the potential to reduce health disparities and improve quality of care. We aim to (1) describe what role(s) RIOAs are/are not taking in their own healthcare, from the perspectives of participant groups (RIOAs, caregivers and healthcare providers (HCPs)); and (2) develop a codesign process with these participants, creating linguistically aligned and culturally aligned tools, resources or solutions to support patient engagement with RIOAs.

Methods and analysis Using a cross-cultural participatory action research approach, our work will consist of three phases: phase 1, strengthen existing partnerships with RIOAs and appropriate agencies and cultural associations; phase 2, on receipt of informed consent, in-depth interviews with RIOAs and caregivers (n=~45) and HCPs (n=~10), professionally interpreted as needed. Phase 3, work with participants, in multiple interpreted sessions, to codesign culturally sensitive and linguistically sensitive/aligned patient engagement tools. We will conduct this research in the Waterloo-Wellington region of Ontario, in Arabic, Bangla, Cantonese, Hindi, Mandarin, Punjabi, Tamil and Urdu, plus English. Data will be transcribed, cleaned and entered into NVivo V.12, the software that will support team-based analysis. Analysis will include coding, theming and interpreting the data, and, preparing narrative descriptions that summarise each language group and each participant group (older adults, caregivers and HCPs), and illustrate themes.

Ethics and dissemination Ethics clearance was obtained through the University of Waterloo Office of Research Ethics (ORE #43297). Findings will be disseminated through peer-reviewed publications, presentations and translated summary reports for our partners and participants.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ We will complete data collection with racialised, immigrant older adults in eight languages, plus English.
- ⇒ We have developed strong community partnerships to support data collection in several distinct ethnocultural communities.
- ⇒ Patients and providers have been engaged throughout, including conceptualisation of the study.
- ⇒ The ongoing COVID-19 pandemic has limited our ability to connect with additional community partners, complete outreach activities and collect data in-person.

INTRODUCTION

More than two million older Canadians are immigrants,[1] and by 2032 one in four older Canadians will identify as a racialised person (persons, other than Indigenous Peoples, who identify as non-Caucasian[2,3]). Racialised immigrant older adults (RIOAs) have a higher prevalence of chronic conditions, poorer self-reported physical and mental health and greater difficulties with instrumental activities of daily living than non-racialised older immigrants and Canadian-born older adults.[4–6] Compared with those who are not racialised, and/or not foreign-born, RIOAs are also more likely to report worse self-rated health, greater disability and functional limitations.[6,7]

The healthcare experiences of RIOAs in Canada

RIOAs in Canada report greater challenges in accessing healthcare and navigating the healthcare system, and face intersecting barriers to care, including literacy, language, culture, health beliefs and spatial and structural inequalities.[7–9] Complexities of family circumstances, immigration status and the healthcare system further compound these challenges.[9] Patients are concerned that their family physicians fail to understand their culture and that their concerns are not being heard due to language and other barriers.[10] In Canada, primary care is viewed, and is intended to serve, as a patient's 'medical home'[11] and serves as the gatekeeper for patients to access other services and other parts of the universal healthcare system (eg, referrals for more specialised healthcare, referrals for home and community supports, etc).

Patient and caregiver engagement in clinical decision-making

There is strong evidence that patient and caregiver engagement within primary care—that is, patients having 'active roles in their own healthcare'[12 13]—leads to improved management of chronic disease,[14] improved patient experience[15] and better health outcomes.[16] Supporting patient and caregiver engagement within primary care has been achieved through healthcare provider (HCP) training, patient education and awareness and shared decision-making approaches and resources.[17] International research demonstrates that patient engagement reduces health disparities, improves quality of care and increases patient satisfaction and confidence.[15 18 19] We completed a scoping review in preparation for this work[20] and can confirm that no peer-reviewed, English language Canadian studies have specifically examined patient and caregiver engagement with RIOAs.

Patient and caregiver engagement in health research

There is growing recognition that patients and caregivers should actively participate in health services research;[21 22] we refer to these efforts as *patient/caregiver partnerships*.[23] A review of patient/caregiver partnering strategies with older adults[22] shows a clear tendency to think of patients/caregivers as a monolingual, culturally homogeneous group. There is limited evidence on developing patient and caregiver partnerships with immigrants and racialised persons.[24]

At present, we do not have an evidence-based understanding of if/how RIOAs are engaged in primary care, which represents both a knowledge and equity gap. Furthermore, patient/caregiver partnership strategies for health systems research have yet to determine how to work in multiple languages, and across different cultural norms and expectations. Without this understanding, both methodologically and empirically, care providers and service organisations are ill equipped to intervene and address the needs of this vulnerable group of older citizens. Finally, the small body of literature on Canadian RIOAs has been exploratory and descriptive (see reviews of references[5 6 8 9]). Solutions-oriented inquiry is a participatory action research (PAR) approach that emphasises the need to move beyond the description of phenomena and towards collaborative action and improvement.[25] PAR prioritises working with key communities and partners to bring about such action.[25] True patient/caregiver partnerships, and PAR, require significant investments of time,[26–28] especially when being mindful and respectful of cultural and language differences.[29]

This paper summarises the research protocol for a multilingual, community-engaged qualitative study that aims to understand the healthcare experiences and patient engagement of RIOAs. Drawing on a transdisciplinary, multilingual team, will do so through intentional patient andcaregiver partnerships, descriptive research, and action-oriented codesign sessions.

OBJECTIVES

The objectives for this work include:

1. to describe what role(s) RIOAs are/are not taking in their own healthcare, from the perspectives of participant groups (RIOAs, caregivers and HCPs); and
2. to develop a codesign process with these participants, creating linguistically sensitive and culturally sensitive/aligned tools, resources or solutions to support engagement of RIOAs in managing their care.

THEORETICAL FRAMEWORK

Our research questions, and approaches to data collection and analysis, are guided by the healthy immigrant literature and intersectionality theory. The healthy immigrant effect posits that immigrants, including older persons, come to North America healthier than their native-born counterparts, but then go on to experience more precipitous declines in health status.[30–32] We know from this literature that racialised persons,[33 34] and those who report that they have experienced racism or discrimination experience worse declines.[30] The healthy immigrant literature is largely quantitative, and researchers have offered three key hypotheses to explain these health declines: selectivity (ie, healthier people move internationally); acculturation (ie, that individuals adopt unhealthy North American habits, such as a more processed diet) and systemic racism (ie, that racialised immigrants experience health declines as they encounter direct and indirect impacts of discrimination).[30 32] The healthy immigrant effect literature also emphasises that a range of variables, including gender, socioeconomic status, life course experience, time of immigration, language abilities and lifestyle impact declines in health status.[35–38] This echoes intersectionality theory,[39] which suggests that to assess and mitigate health and social inequities, researchers much examine the simultaneous intersections of statuses related to social identity, including but not limited to ethnicity, race, age, gender, socioeconomic status, migration status, religion and disability.[40] The healthy immigrant effect literature and intersectionality theory will inform all aspects of our research, from the research questions through analysis and outputs.

RESEARCH DESIGN

With a focus on solutions-oriented inquiry,[25] and using a cross-cultural qualitative PAR approach,[41] we will: phase 1, *actively engage in partnerships* with RIOAs and appropriate agencies (to continue throughout the project);

phase 2, *describe* the role of RIOA patients, through interviews with RIOAs, caregivers and a range of HCPs and phase 3, begin the *codesign* of resource(s) to support patient and caregiver engagement with RIOAs. We will employ an integrated knowledge translation approach,[42] working with partners and RIOAs to collectively answer our research questions; consistent with the values of PAR, we have already engaged in pilot work and engagement with a range of community representatives to develop our research questions and methodological approach. Although we present our work in a linear fashion, we know that iKT and PAR are both iterative processes in which we engage in continuous learning and refinement by working with our partners.[42 43]

Older adults' engagement in cross-cultural PAR

PAR emphasises that the individuals impacted by research problems and questions should be engaged in all aspects of a study, from inception through knowledge translation. For qualitative cross-cultural PAR, we are guided by Liamputtong's[41] seminal work on this topic; specific to engagement with older adults, we are guided by Marlett and Emes.[44]

TERMINOLOGY

We recognise that many of the terms that we use in this protocol are contested and debated in the academic literature, particularly those related to race, ethnicity and identity.[45] The terms that we use, for example, to refer to ethnocultural groups (eg, South Asians), or 'older adults' are socially constructed, but we believe in some ways reflect the lived realities of our target participants.[46] We also acknowledge that in using terms such as 'South Asian', we are reinforcing colonial narratives regarding borders and belonging.[47] The terms that we use are outlined below, and we will continue to reflect on: how we speak about and label our participants, and if/how this may impact future analyses.

Racialised and visible minorities

There are many terms that refer to people, in a Western context, who are not white; for example: visible minorities, POC/persons of colour and BIPOC (Black, Indigenous and Persons of Colour). Statistics Canada continues to use the term 'visible minorities',[48] but we opted to use the term racialised, which is preferred by the Ontario Human Rights Commission (OHRC).[49] Many of our community partners do not understand or recognise the newer term 'racialised', and there has been some debate regarding this term.[50] We have opted to use this term because we concur with Hochman, who notes that the term racialised is of importance, 'as it offers a way for groups that have been understood and treated as inferior "races" to assert and defend themselves collectively, while rejecting the biologization and inferiorization associated with "race"' (p. 12).[45]

Older adults

Definitions and chronological cut-points to determine who is an 'older adult' vary, and can also vary by context (eg, in some Indigenous communities, among persons experiencing homelessness and other marginalised communities, the cut-point for 'old age' can be as low as 45–50 years). In Canada, this also varies, with many using 65 years, which is tied to the previous age for retirement from the workforce. Because we are recruiting older adults who were born in various countries, we opted to use the WHO's cut-point of 60 years.[51]

Foreign-born

Many terms are used (sometimes inconsistently or incorrectly) to describe individuals who were born in one country, and at some point in their lives relocated and settled in another. Terms used to describe this group can include diaspora, ethnoculturally diverse, immigrants, migrants, minority, newcomers, new settlers, transnational, etc. For our work, we use the term foreign-born, which does not denote when they relocated and/or the ways in which they arrived (ie, various immigration steams, and/or modes of transnational movement that are not legally recognised). In our view, foreign-born is an immutable status, not tied to legal designations and does not refer to specific ethnicities, cultures or visible minority/racialised status.

Caregiver

We use the Change Foundation definition of caregivers: a person—family member, friend, neighbour—who provides important care, usually without pay.[52] Caregivers do not need to coreside, be related or be of a particular age.[52] We anticipate most caregivers of RIOAs will be family members, but this is not a requirement (see below for our inclusion and exclusion criteria).

METHODS AND ANALYSIS

Setting, context and research team

We will conduct this research in the Waterloo region of Ontario, Canada (home to three medium-sized cities and several rural towns). While findings from the Waterloo region may be transferable to analogous medium-sized cities, it is unique in that it is a refugee settlement region. We may be more likely to recruit refugees, compared with other regions. The region may also be more likely to have multilingual care providers and immigrant resources/support services, compared with other medium-sized cities that are not settlement areas.

In developing this protocol, we held a focus group with HCPs in the region, and they recommended that we work in Mandarin, Cantonese, Arabic and several South Asian/Indo-Aryan languages, which is reflective of the local population.[53] Our team includes multilingual undergraduate and graduate students, clinicians (family physician and pharmacist), and early and late career researchers with expertise in: health equity, intersectionality, cross-cultural qualitative research, social gerontology, immigrant health, patient engagement, and geriatric healthcare.

We received funding for this work in Spring 2021, and data collection began in September 2021. We will continue linguistically phased interviews through December 2022, and linguistically phased codesign sessions from January to May 2023, with analysis embedded throughout.

Phase 1: Partner and community engagement

We will draw on cross-cultural participatory methods[41] to guide partnership development and include patients in each phase of the research.

Existing partners and fostering new relationships

We have existing partnerships with a range of healthcare organisations in the region, including several primary care practices and family health teams. Through personal and professional networks, we are connected to local South Asian, Arabic, Black and Chinese cultural associations, many of whom officially endorsed this research when we applied for funding. We will continue to work on outreach and community engagement, to broaden our reach for both recruitment and future Knowledge Translation (KT) efforts. For the duration of the project, we will attend strategically selected events to raise our visibility and engage with RIOAs, however, many events have been cancelled due to the ongoing COVID-19 pandemic. In year 1, we have attended events with local Muslim women (connecting to both Arabic-speaking and some South Asian communities), online mindfulness workshops with South Asian older adults and local events to commemorate Chinese New Year and Ramadan. We will use a range of communication methods to connect with older adults, including mail, email, telephone and popular apps (eg, many of our Arabic-speaking participants in year 1 have reached out regularly via WhatsApp), and in-person, to be as inclusive as possible.

Phase 2: Interviews

We will interview RIOAs, caregivers and a range of HCPs. The aim of these interviews is to describe the current state of patient and caregiver engagement, understand mitigating factors (including intersecting statuses of gender, ethnicity, age, and socioeconomic, per Hankivsky[40] and identify opportunities for future interventions and supports.

Recruitment and eligibility criteria

For recruitment, we will use digital posters, physical posters in community spaces and emails with partners identified in phase 1. Our initial recruitment modes are largely limited to online, virtual modes, on account of the ongoing COVID-19 pandemic.[54] We will also ask participants to support snowball sampling, particularly to potential participants who are less likely to be connected online; this approach can support access to harder-to-reach populations.[55] We are recruiting RIOAs and caregivers though community organisations, and not through their clinics or providers, with the hope that this approach will allow participants to speak more freely about healthcare experiences.

Eligible HCPs are any providers who serve RIOAs in the region, and could include physicians, nurses, pharmacists and others. Eligible RIOAs are foreign-born persons aged 60+ who live in the region and can complete an interview in English or one of our eight target languages (Arabic, Bangla, Cantonese, Hindi, Mandarin, Punjabi, Tamil and Urdu). While information on participant ethnicity will be asked for demographic information, we aim to strategically recruit racialised persons/individuals of colour based on language (not ethnicity or race). Individuals from all immigrant streams (eg, family, economic and refugee) and any length of time in Canada (eg, newcomers and longer term immigrants) are eligible. Eligible caregivers are any individuals who provide care to RIOAs, including care of older adults who are not study participants. We will encourage (but not insist) older adults and their caregivers be interviewed separately, in the language of their choice, to ensure individual voices and perspectives are heard and documented.

Given immigration trends to the region, we expect that it will be possible to connect with older adults and/or caregivers supporting RIOAs who speak South Asian and Chinese languages, but it may be more difficult to recruit sufficient Arabic-speaking participants, as this is a comparatively smaller and younger group.

Interested participants will be provided, via email or the post, with a letter of information outlining the study, in the language of their choosing. At the start of each interview, participants will be asked to verbally provide informed consent, using a consenting script and this will be documented. The letter of information has been professionally translated into our study languages, and where needed, the verbal consenting process will be supported by a professional interpreter (see also Translation and interpretation approach below).

Sample size

Our approach to determining sample size is informed by Vasileiou *et al*'s systematic review of samples in qualitative health research, which emphasises *data adequacy*.[56] Data adequacy focuses on obtaining thick and rich data that sufficiently captures participants' stories, offers different types of evidence (eg, interviews, focus groups and codesign), different perspectives and disconfirming evidence (ie, 'outliers'). Conceptually, data adequacy moves beyond the 'N' to consider the nature of evidence and robustness of the analysis. We have estimated between 10 and 20 interviews/group (10 HCPs, and for older adults and caregivers, a total of 10 Arabic, 20 Bangla, Hindi, Punjabi Tamil, Urdu, 15 Cantonese and Mandarin); these sample sizes are reflective of the local immigrant population, and similar sample sizes allowed us to adequately answer research questions in our prior work with diverse RIOAs.[57 58]

Table 1 Sample interview guide questions

Older adult interview guide—sample questions	What do you do to look after your health? What role do family members play in your healthcare? Do you feel like you can ask your healthcare provider(s) all of your questions? Why or why not?
Caregiver interview guide—sample questions	What supports would be most useful to you as a caregiver? What unanswered questions do you have about the Ontario or/and local healthcare systems? What improvements or changes do you think could be made to the current healthcare system in Ontario to make it better suited for immigrant older adults?
Healthcare provider interview guide—sample questions	Are there supports or resources in your practice that help you care for RIOAs? What barriers or challenges have you faced in providing care for RIOAs? Other than language/translation, what is the number one thing you would like to work on or change to support the care of RIOAs?

RIOAs, racialised immigrant older adults.

Data collection

Interviews will follow semi-structured interview guides[59] and be digitally recorded. Due to the ongoing COVID-19 pandemic, interviews will primarily take place over the telephone, or using videoconferencing software, at a time of the participant's choosing. Questions will examine how RIOAs are currently engaged in their healthcare, how they make decisions with HCPs and the role of family caregivers in these processes. Interview guides will be slightly modified for each linguistic group (eg, in Cantonese and Mandarin interviews, we will probe specifically for the use of Traditional Chinese Medicine and those healthcare experiences). Older adult participants and caregivers will also complete a brief survey capturing key demographic data, and reflective of an intersectional approach, including age, gender,[60] ethnicity, country of origin, immigration history and stream, language spoken, capacity to communicate in English, education, household income and overall self-reported health. The HCP survey will collect demographic data, including roles and length of time in the profession. We have tested these interview guides, and specific questions, in pilot work and in previous patient engagement research.[61] The interviewer and multilingual research assistant (RA) will debrief and compose detailed fieldnotes after each interview.[62] In primary care, HCP's time is limited. We may conduct HCP interviews using a focus-group format to minimise impact on their time.[63] Sample interview guide questions are presented in table 1.

Translation and interpretation approach

Data collection with HCPs will be completed in English. Data collection with older adults and families requires a thoughtful translation and interpretation approach. All recruitment and consenting materials have been professionally translated. We will hire multilingual, part-time RAs to assist with recruitment, scheduling interviews with participants, etc. Each older adult/caregiver interview will be led by a member of our team, with the assistance of a local professional interpreter, as needed (in our experience, some RIOAs will want to be interviewed in English[58]). We will use consecutive translation[64] and a combination of multilingual RAs and transcribing software (Otter.ai) to prepare English-language transcripts of the interviews. We have protocols developed to support this process, and we have extensively tested this translation and interpretation approach in prior studies.[57 58] Two to three translated and transcribed interviews from each language group will be randomly selected for the translation to be reviewed and confirmed by a second, multilingual RA; again, we have used and tested this approach in prior work.[57 58]

Data analysis

We will upload transcripts and fieldnotes/debriefing notes into NVivo V.12[65] software. We will then use line by line emergent coding techniques, as outlined by Saldaña,[66] to code data. The qualitative analysis will follow three steps: (1) coding, theming and interpreting the data: researchers will read through the data set and create codes using NVivo V.12. We will then identify themes using a clustering technique.[67 68] Each cluster will have a proposed name, brief description, illustrative quotations from the data and a list of codes that support the theme; (2) extensive memoing and team-based analysis meetings will take place throughout the theming and interpretation phase and (3) narrative descriptions will be prepared, including quotes, that summarise each language group and each participant group (older adults, caregivers and HCPs) and illustrate high-level themes. In our analyses, we will report gender when using participant quotes and data. Where appropriate/relevant, we will report findings for the total sample and disaggregate them by gender, in accordance with the SAGER guidelines;[69] we will achieve this by specifically coding for gender, and the intersection of gender with other statuses (eg, age and ethnicity), per intersectionality theory. Survey data will be entered into both NVivo V.12, to inform qualitative analysis, and SPSS (quantitative software). We will summarise demographic data using medians for scale variables and frequencies for categorical variables. The survey data will only be used to describe the sample, as cells will be too small for most statistical analyses.

Phase 3: Multilingual codesign sessions

Codesign is a solutions-focused, participatory process in which patients and heathcare staff work together to identify solutions, strategies and goals to improve the delivery of care.[70] One of the principles of genuine codesign is to enter the process without predetermined results.[71] Because we are working in multiple languages, we will take a phased approach to the codesign sessions. We have not seen any guidance in the codesign literature regarding a multilingual approach, and we will carefully document our process for future efforts to offer codesign in a linguistically inclusive manner; we anticipate that this will be an important contribution to the codesign literature. Our documentation of the codesign sessions will include audio recordings, ethnographic style fieldnotes[62] and a postcodesign survey (translated as needed) for participants to share their experiences in these sessions. We will share translated letters of information in advance of the sessions, with participants who expressed an interest in being part of the codesign process. If online, we will verbally confirm informed consent prior to the sessions, using a consenting script; if in-person, participants will be asked to sign a consent form. As above, all recruitment and ethics documents have been professionally translated.

Round 1: Interpreted codesign sessions

These initial codesign sessions (2 hours, in Spring 2023) will be with RIOAs and caregivers, recruited as a subsample from the phase 2 interviews, and will be separately conducted in the study languages (many of our South Asian participants speak several languages, and one Hindi session may serve many participants). Each of the round 1 interpreted sessions will include a professional codesign facilitator, RAs, approximately 2–3 participants (older adults and caregivers), and an interpreter to facilitate same-language discussions. Pending guidance regarding the ongoing COVID-19 pandemic, these sessions may be in-person or online. We have prior experience in conducting interpreted, multilingual, online focus groups in several languages.[72] The objective of round 1 will be for older adults and caregivers to review findings from phase 1 and identify potential solutions.

Round 2: English codesign session

This session (one half-day, with breaks, refreshments and staff back-fill provided, in Spring 2023) will include RIOAs (n~3), caregivers (n~3) and HCPs (n~3), again a subsample from phase 2 interviewees, who are willing and able to participate in an English-language session. This session will also be professionally facilitated. In round 2, participants will review the potential solutions from round 1, discuss pros and cons of each solution, vote on their chosen solution(s) and create an action plan to inform next steps. Further developing and implementing the codesigned solution will form part of a subsequent implementation project.

Patient and public involvement

Our team has a longstanding commitment to doing research with and for older adults,[22 28 58 72–74] and we worked closely with RIOAs, caregivers and HCPs to develop this protocol. Patients, caregivers, providers and community partners have or will be involved in conceptualisation of the project and pilot data collection, recruitment efforts, data collection, codesign sessions and copresenting our findings at healthcare and academic conferences. Patient partners have provided input on the mode of data collection, the length/time commitment for potential participants and the nature/phrasing of our interview questions. Patient partners have also generously reviewed our professionally translated documents to ensure readability for their respective communities.

Ethics and dissemination

Ethics

We received ethics clearance from the University of Waterloo's Office of Research Ethics (ORE #43297). We are also mindful of van den Hoonaard and van den Hoonaard's[75] guidance on ethical qualitative research with vulnerable populations.

Dissemination

Together with research participants, we will present the findings from our research in two local, well-attended annual primary care conferences. We have budgeted for patient and caregiver partners to attend these conferences. We will prepare knowledge briefs, and translated plain language summaries, to share with interested and relevant parties. Dissemination will also include peer-reviewed manuscripts in open access journals, plain language and multilingual summary reports for our participants.

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