

Older Adults' Views on the Repositioning of Primary and Community Care*

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RÉSUMÉ

Notre recherche a exploré les perspectives des personnes âgées sur le “repositionnement”, une initiative de restructuration visant à soutenir la vie autonome des personnes âgées atteintes d’une maladie chronique complexe (MCC). Nous avons collecté et analysé des données de 83 personnes âgées d’une petite ville et de neuf petites villes rurales où l’initiative de repositionnement se passe. L’âge moyen des participants était de 75 ans. Les participants comprenaient 56 (67%) femmes, 44 (53%) vivaient avec une MCC et 20 (24%) étaient Indigènes ou Sud-asiatiques. Il y avait quatre thèmes: méconnaissance du repositionnement, optimisme versus scepticisme, amélioration des soins primaires et communautaires, et jouant un rôle actif dans le changement. Pour que le repositionnement réussisse, il faut inclure tous les types d’utilisateurs de services et plutôt que d’adopter un approche générale, il faut prendre en considération les priorités des soins primaires et communautaires des personnes âgées vivant en milieu rural.

ABSTRACT

Older adults are rarely consulted on health care restructuring. To address this gap, our study explored older adults’ views on “repositioning”, a restructuring initiative to support independent living for older adults with complex chronic disease (CCD). We collected and analysed data from 83 older adults living in one small city and nine rural small towns where “repositioning” of primary and community care was occurring. Average participant age was 75 years; 56 (67%) were women, 44 (53%) had CCD, and 20 (24%) identified as Indigenous or South Asian. The four themes were: unfamiliarity with repositioning; optimism versus skepticism; improving primary and community care (through better home care, improved transportation, and more doctors); and, playing an active role to effect change. For repositioning to be successful, diverse service users must be fully included; rural-dwelling older adults’ priorities for primary and community care need to be addressed, rather than using a “cookie-cutter” approach.

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Introduction

Demand is increasing for primary and community care services for older adults who have multiple and interconnected health needs. Health systems are attempting to align care delivery models in a way that will cater to the holistic needs of older adults and improve accessibility to primary and community care services. Like the rest of the country that is responding to a rapidly aging population with complex health needs, British Columbia (BC) is redesigning services to support older adults to remain at home longer, with a particular focus on “frail elderly” (age 75 years and older) and rural communities (Ministry of Health, 2015a). For Interior Health, this “repositioning” initiative meant a shift in resources from acute care to primary and community care to better support independent living at home or in the community and, at the same time, to reduce hospital and residential care admissions (Ministry of Health, 2015a). This initiative, which began in 2015, was driven by a projected increase in the senior population (defined as those aged 65 and older) of 20 per cent between 2014 and 2019 in Kamloops (one of two small cities in Interior Health’s catchment area) and was in the planning stages when we conducted the research reported herein. One of the proposed outcomes of the repositioning initiative was a seniors’ health and wellness centre in Kamloops which opened after we completed this research.

Notably, this restructuring came on the heel of serious cuts to home and community care services. Between 2001 and 2010, there were major reductions to home and community care services in British Columbia, including residential care (21%), home support (30%), and home nursing care (3%) (Cohen, 2012, p. 6). These reductions varied across the province with some health authorities being more affected than others, Interior Health being one of them. Despite the aging of the population – 18.8 per cent of British Columbia residents are aged 65 and older (BC Stats, Ministry of Jobs, Trade and Technology, 2018, p. 5) – older adults in British Columbia have less access to services today than in 2001 (Cohen, 2012; Longhurst, 2017). This is the result of 16 years of “underfunding, privatization and fragmentation of the

system [which has] left many seniors, their families and communities patching together care – and even going without” (Longhurst, 2017, p. 4).

Based on a directive from the Ministry of Health, Interior Health held informal consultations in 2015 with service providers, older adults, and family carers in Kamloops and formed a local action team to develop a new care delivery model. The Researching Older Adults’ Repositioning (ROAR) study aimed to inform the development of this model. Critical gerontological researchers and health authority decision-makers collaborated to ensure that the model arising from repositioning would reflect the needs and desires of older adults in rural towns served by the health authority as well as the needs and desires of those older adults who had not participated in the initial Kamloops consultations. Since evidence-based practice is focused on research evidence, clinical expertise, and client preferences (Melnyk & Fineout-Overholt, 2015), the ROAR research aimed to engage a diverse population of older residents of Kamloops and surrounding rural small towns to share their views on Interior Health’s repositioning. We were particularly interested in hearing from rural, low-income, ethnic minority, Indigenous, and sexual minority older adults as they were not involved in the initial Kamloops consultations.

We applied an integrated critical gerontology and social determinants of health (SDOH) framework in designing and operationalizing this study. A critical perspective on aging (Estes, Biggs, & Phillipson, 2003; Funk, 2016) ensured that we attended to the political-economic context of care, which includes SDOH, and that we treated older adults as a diverse, heterogeneous group whose voices and experiences were important. We drew specifically on anti-oppression gerontology (Hulko, Brotman, & Ferrer, 2017; Hulko, Brotman, Stern, & Ferrer, 2020) which seeks to eliminate discrimination and promote inclusion for older adults from equity-seeking groups and foregrounds agency, equity, resilience, and resistance. SDOH are “the economic and social conditions that shape the health of individuals, communities and jurisdictions as a whole” (Raphael, 2009, p. 2) or, more generally, “the conditions in which

people are born, grow, live, work and age" (World Health Organization, 2013). Research on rural aging treats seniors with health problems as "marginalized", yet often overlooks poverty and gender (Keating, Swindle & Fletcher, 2011) despite these being key SDOH.

Literature Review

We conducted a methodical search of select databases (Web of Science, Social Services Abstracts, Social Work Abstracts, Google Scholar, CINAHL, Medline) for relevant literature from Australia, the United Kingdom, the United States, Europe, and Canada that had been published in the past 10 years. We found a great deal of research on models of care for older adults, including integrated care, shared care, and other team-based approaches, and some research on the utilization and restructuring of health services in rural communities. A few studies on the design and delivery of community-based health care (Averill, 2012; Grimmer, Kay, Foot, & Pastakia, 2015; Lafortune, Huson, Santi, & Stolee, 2015; Petriwskyj, Gibson, & Webby, 2014; Spoorenberg et al., 2015) and on health care restructuring (Bascu et al., 2014) have included the perspectives of older adults – as clients, patients, consumers, and/or service users.

Service User and Provider Views on Community-Based Care

In an Ontario study of community-based care, 28 clients and informal caregivers and 20 health care providers were asked through focus groups about their recommendations for system improvement (Lafortune et al., 2015). Participants – both urban and rural – identified a need for the expansion and integration of care teams, system navigation, and standardized assessments, information systems, and care pathways; rurality did not affect the results except for transportation (as a barrier only for the rural participants). A qualitative study on integrated care models in the Netherlands gathered the opinions of 23 community-living older adults receiving integrated care and support, resulting in three themes related to care: (a) relationship with the case manager, (b) interactions, and (c) feeling in control, safe, and secure (Spoorenberg et al., 2015).

Another qualitative study with 42 community-dwelling older adults in Australia determined key elements of aging-in-place to be (a) health, (b) information, (c) practical assistance, (d) finance, (e) activity (physical and mental), (f) company (family, friends, neighbours, pets), (g) transport, and (h) safety (Grimmer et al., 2015). Another Australian study on client engagement in aged care services (community, residential, retirement living) collected data from 85 clients and 94 staff through interviews and focus groups (Petriwskyj et al., 2014). The

researchers found that clients were positioned as disempowered; experts or consumers; resistant or non-compliant; or diverse in their needs and wishes. Through this research, they expressed the need to give clients the opportunity to share their preferences and choices as engaged partners in the provision of services.

Utilization and Restructuring of Health Services in Rural Communities

Studies on the utilization of health and support services and the impact of restructuring have been conducted in rural and northern British Columbia (Allan & Cloutier-Fisher, 2006; Hanlon & Halseth, 2005; Hanlon, Rosenberg, & Clasby, 2007; Ryser & Halseth, 2011) and in other rural communities across Canada (Bascu et al., 2014; Davenport, Rathwell, & Rosenberg, 2005; Keating et al., 2011; Skinner et al., 2008), yet only one of these studies included service user views (Bascu et al., 2014). Bascu et al. interviewed 40 older adults from two rural communities in Saskatchewan, in their homes, to determine policy, community, and kin interventions to support rural aging-in-place. Home care and health services were two of the policy interventions, and transportation was a significant concern.

From this review of the literature, we determined that there is little on the design and delivery of health care services, including restructuring efforts, that (a) focuses on rural and remote communities, (b) includes the views of older adults as service users, and (c) considers SDOH. Thus, our research sought to address this gap through using an integrated SDOH and critical gerontology framework.

Research Design and Methods

The ROAR study used a qualitative approach to explore older adults' views on the repositioning that Interior Health was undertaking to support independent living and reduce admissions to hospital and residential care for older adults with CCD. The research questions were as follows:

1. What are older adults' views on the repositioning of primary and community care in British Columbia's Central Interior region?
2. How might this repositioning best meet the needs and reflect the desires of older adults?
3. What should the role of older adults be with respect to the repositioning of health care?

We received ethical approval from the Thompson Rivers University and Interior Health human research ethics boards in summer 2016; both certificates were renewed in 2017, and the study closed in 2018.

Sampling and Recruitment

One small city (Kamloops, population 90,280), two rural towns (Merritt and Williams Lake, population 7,610 and 11,215 respectively), and 7 rural small towns (100 Hundred Mile House, Ashcroft, Barrier, Chase, Clearwater, Lillooet, and Logan Lake, population range 1,555 to 2,413) in the Interior Health west service area were selected to participate in ROAR. Our definitions of rural and small rural towns and urban centres are based on the Ministry of Health (2015b) community and hospital classification framework. The residents of all these communities access Royal Inland Hospital in Kamloops rather than other tertiary hospitals in the region and are between 57 and 288 kilometres away from Kamloops. Both small cities (Kamloops and Kelowna) in the Interior Health region were mandated to engage in repositioning and our research focused on Interior Health West.

We sought to recruit 100 community-dwelling older adults, 60 per cent of whom were to be rural residents and 40 per cent from Kamloops, with an estimate of 6–8 participants per participating rural community. We used convenience and snowball sampling to recruit ROAR participants through Interior Health (home and community care, walk-in clinics), the Council on Aging, existing social groups and events (e.g., Elders' luncheons, Soup's On), and local seniors' centres in each of the participating communities, with an emphasis on those older than age 75 and those living with CCD. Our research assistants contacted key people in each community to put up posters and circulate study invitations; and the research team attended numerous events to promote the study and made several recruitment trips to rural communities to secure participation. Participants received a \$20 gift card to a grocery and/or drug store in their community. To increase representation and/or to diversify our sample, we made repeat visits to some communities (100 Mile House, Lillooet, and Williams Lake) and arranged for a Punjabi interpreter for an additional Kamloops focus group at the Sikh temple. Two of the four focus groups in Kamloops were with First Nations Elders, one being at the Aboriginal Friendship Centre. We returned to Lillooet to hold a focus group in a First Nation community (Bridge River) upon their request. Our repeat efforts to hold a ROAR focus group with older sexual and gender minorities were unsuccessful, and only one participant disclosed their sexual minority status on the demographic form.

Data Collection and Analysis

We collected data through 15 focus groups (FG) and nine individual interviews (Int) to garner older adults' views on "repositioning" (see interview guide in Appendix 1). Focus groups allow for in-depth

discussion of specific questions, with participants building on each other's views and experiences until common themes begin to emerge (Krueger & Casey, 2000). Focus groups allowed us to generate a great deal of information in a short period of time, which was important as we were unable to make return visits to most of the communities during the data collection phase. In contrast, individual interviews enabled the "detailed pursuit of content information" (Berg, 2004, p. 127) and increased diversity within the sample by facilitating the participation of those reluctant to express their views in front of others. The majority of those who took part in interviews were women, including the one participant who identified as a sexual and/or gender minority.

All participants completed a 10- to 15-minute consent process and socio-demographic questionnaire before the interview or focus group began. Focus groups comprised two to 10 participants (median of five) and duration lasted between 44 minutes and 2 hours and 37 minutes, with an average of 1 hour and 17 minutes. We conducted interviews in person, often at the same venue as the focus group (except for one by phone), and they averaged 30 minutes in length. Both individual interviews and focus groups were audio-taped and then transcribed by a professional transcriber. Field notes were taken by research assistants, with a focus on describing the setting and capturing non-verbal cues to assist with analysis and interpretation.

Qualitative data analysis is time-consuming as it involves "working intensely with rich data" (Bazeley & Jackson, 2013, p. 68) and consists of various activities such as reading, reflecting, coding, annotating, memoing, discussing, linking, and visualizing. We used NVivo 10 (qualitative data analysis software) to assist in this process as it enables comparisons to be made across participants and communities, and supports the aforementioned activities. We undertook a blend of conventional and directed content analysis (Hsieh & Shannon, 2005) as codes were both inductively and deductively derived. Hsieh and Shannon have defined qualitative content analysis as "a research method for the subjective interpretation of the content of text data through the systematic classification process of coding and identifying themes or patterns" (p. 1278). Content analysis is similar to qualitative description (Bradshaw, Atkinson, & Doody, 2017) in that both are used in health research to understand participants' perspectives on a particular phenomenon or process (i.e., repositioning). To prepare the research team for qualitative data analysis, the first author who was a co-principal investigator (co-PI) led a data analysis workshop which included guidance for the community-based researcher (CBR) on how to code the transcripts based on the three study questions and an initial codebook.

The initial codebook included “repositioning”, “primary care”, “community care”, and “social determinants of health” with a description of when to apply each code and examples from the data. The codebook was further developed by the same co-PI and CBR who added inductive codes, including in vivo ones, and the final version had close to 40 codes. Whereas codes are a means of identifying themes observed in the data, this first coding stage was more descriptive or topical than interpretive or analytical (Bazeley & Jackson, 2013, p. 70). The CBR wrote memos while coding in NVivo and engaged in regular peer debriefing with both co-PIs (the first and second authors). After the initial coding, the co-PIs then undertook a more in-depth analysis of the codes, seeking not only to generate themes (i.e., clustering and collapsing codes), but also to interpret the study findings based on the ROAR theoretical framework. This included comparing the top priorities by communities and by Indigenous status and ethnicity to uncover similarities and differences. The research team discussed preliminary findings with the advisory committee (decision-makers and knowledge users) and returned to participating communities to share the findings and receive feedback as a form of member checking. We arranged information sessions through our recruiting sources (e.g., local seniors’ centres) and personally invited study participants. These sessions were also advertised to older adults in general, thus the attendees were a mix of participants and interested parties. We did not identify the study participants in order to maintain anonymity. These techniques (memoing, peer debriefing, member checking) all served to ensure the rigour of our research.

Results

The ROAR sample was made up of 83 community-dwelling older adults. This was lower than the estimate of 100 as, when close to data saturation (Bakers & Edwards, 2012), we reallocated funding to enable Punjabi-speaking older adults to participate. Of the 83 participants, 61 (73.5%) were from the participating rural towns and 22 (26.5%) were Kamloops residents. Given that the Interior Health repositioning consultations had involved Kamloops older adults only, we were pleased that our rural participation was greater than 60 per cent. The average age of participants was 75 years (range of 62–89 years); 56 (67%) were women, and 27 (33%) were men; 13 (16%) identified as Indigenous and 7 (8%) as South Asian; and 44 (53%) had complex chronic disease (CCD). The majority (58%) of ROAR participants were living on less than \$30,000 per year, with 24 per cent of the sample having an income of less than \$15,000 per year. Sixty-four per cent of the women and 48 per cent of the men lived alone, and a

greater number of women (16%) than men (7%) resided in assisted living or a group home. The relationships between these data on the social determinants of health (SDOH), gathered through the socio-demographic questionnaires, along with our participants’ views on SDOH will be the focus of another article due to space limitations.

The following themes were derived from our in-depth analysis of the coded data from the focus groups and interviews: unfamiliarity with Interior Health’s repositioning; optimism versus skepticism; improving primary care and community care (through better home care, improved transportation, and more doctors); and playing an active role to effect change.

Unfamiliarity with ‘Repositioning’

The overwhelming majority of participants were unfamiliar with the meaning of the word repositioning. For example, a focus group participant in a small rural (SR) town said: “Where did that word ever come from? ... Repositioning means [to us] to relocate from the country to the city” (FG, SR3). Another rural participant said, “I still have a problem with these general terms – repositioning and so on, because you don’t know what it means, and it could be very specific to different communities” (FG2, SR5). Not only was the word unfamiliar, but there was also next to no awareness of the health authority’s specific repositioning initiative as this focus group discussion indicates:

P1: “I have heard nothing.”

P2: “I have heard nothing.”

P3: “By repositioning, what do you mean?” (FG, SR4)

After participants displayed their unfamiliarity and/or asked for the meaning of repositioning, we provided the Ministry of Health (2015a) definition (see Appendix 1); this includes a focus on adults aged 75 and older with complex chronic disease (CCD) and refers to a shifting of resources within the health care system to reduce hospital and residential care admissions. After learning about repositioning, participants expressed optimism or skepticism, and this varied depending on whether they lived in Kamloops, an urban (U) centre, or one of the rural (R) or small rural (SR) towns. This is the only theme that included contrasting opinions based on rural or urban residency.

Optimism (in Urban Centre)

The views of the older adults living in Kamloops were marked by optimism with participants referring to the anticipated result of “keeping people well at home”. For example, an Indigenous Elder in Kamloops stated, “I think [repositioning] will be a great step towards keeping people well at home as opposed to everybody

heading to emergency and going to the hospital" (FG2, U, Indigenous Elder). This optimism was connected to the physical relocation of some of Interior Health's services from the South Shore to the North Shore for those participants who learned of this plan during the course of the research. In response to this, a Kamloops participant said "Oh yeah, it would be nice to have one [Seniors' Wellness Centre] on each [side of the river] because I know there's a lot of people on the South Shore that have to come here [North Shore] to get a lot of things and vice versa" (FG1, U). A South Asian older adult also liked the idea of a North Shore Seniors' Wellness Centre, noting "I think [it] is very good for our community because we are all living in the North Kamloops" (FG4, U, South Asian). This optimism in Kamloops contrasted with a pronounced skepticism on the part of those living in rural and small rural towns. None of the rural participants expressed optimism about Interior Health's repositioning.

Skepticism (in Rural and Small Rural Towns)

Rural-dwelling older adults viewed repositioning from a skeptical lens, stating, "The theory is wonderful, but how is it going to hit the dirt, how is it going to come into form ... At the moment, it's a wonderful theory, but it's just that" (FG, SR3). Participants in other rural communities questioned the health authority's idea of "support": "I know of no support that is coming forth ... if there's some out there, I want to hear about it ... I'm all in favour of independent living, keeping people in their homes, but where's the support for that?" (FG1, SR5). They also questioned the motivation of the health authority, suggesting in an interview that it might be a way to reduce staffing: "I think that would be wonderful if it was well done. But if it was, if they are just doing it to reduce staffing or whatever and nothing is actually going to end up in place to help the people" (Int, SR7).

This skepticism was related to past government promises that were not actualized or that failed to effect meaningful change in the delivery of primary and community care: "I'm a little skeptical about whether they're going to [do it] ... because they sorta dropped the ball last time they screwed things around" (FG, SR2). There was mention of a specific government policy document on primary care "from 1972 when Marc Lalonde was the Federal Minister of Health" and the fact that "you can measure in millimeters the distance it's moved" (FG, SR3). Based on their skepticism and disappointment with past promises, members of the same small rural town suggested that another term would soon replace this one, with one older adult musing: "I'm wondering when someone like you is going to be coming and asking us about their new word, because this one is repositioning" (FG, SR3).¹

When reflecting on specific challenges associated with rural living, participants stressed that "rural health care is not mini-urban; it's different" and "it doesn't make sense to try to solve rural problems in an urban setting because they're not the same ..." (FG, SR3). The way that Kamloops or Kelowna (the other small city in the Interior Health region) design and deliver health care is not necessarily going to work in small rural towns, as the following quotes indicate: "Kamloops has no idea what we need and why should they" (FG, SR4), and "What might work in Kamloops will not work in [name of small rural town]" (FG1, SR5). Participants termed this application of small city or large urban centre solutions to small rural towns a "cookie cutter" approach, stressing that "the cookie cutter that fits over the urban situation is not going to fit on this one" (FG2, SR5). Solutions that fit the local context are critical to rural residents, with an emphasis being placed on practicality: "Restructuring has to be practical if it's to exist at all in the rural communities" (FG1, SR5).

Improving Primary and Community Care

When asked about how the repositioning could best meet their needs and reflect their desires, participants talked at length about what they hoped would result from Interior Health's restructuring efforts in relation to their home communities. This included better home care services; improved transportation; and more doctors, knowledgeable doctors, and "proper" doctors. These were the top priorities for all participants, regardless of whether they lived in a rural town or the small city.

Better Home Care Services

The need to increase the number of hours that home care provides to older adults as well as to expand the number of tasks that can be performed was one of the top three priorities for ROAR participants. A rural participant spoke of home support workers not being able to "help you with something that you need a little help with", noting "they used to be able to easily clean the bathroom ... 'cause that's a vital part and to make a sandwich or leave something for supper ... but they are not allowed to [do that anymore]. There is a lack of common sense ... And I think that is what's needed is more common sense ..." (FG, R2). This missing "common sense" was the realization that providing assistance with household tasks can support older adults to stay at home longer and delay transitions to residential care. Further, this is in accordance with the desires of older adults: "I think it would be a lot better to have a little more home care support rather than going into a facility" (FG, SR6).

- Scheduling HandyDart for appointments that can't be pre-booked (e.g., walk-in clinic)
- Appointments (e.g., with specialists in urban centres) are not coordinated with transportation
- Getting to pick-up points for Health Connections Bus (that takes rural residents to appointments in urban centres)
- Difficulty communicating with drivers (e.g., due to language barriers and sensory impairments)
- Having to rely on friends, neighbours, and family members for rides which creates dependency
- Reimbursement for travel is less than actual costs (e.g., fuel costs for old cars, hotels, meals)
- Difficult driving conditions due to winter weather, and long distances block access to health care services and lead to less frequent (e.g., monthly) and shorter visits by health professionals

Figure 1: Multi-faceted nature of transportation issues for older adults

ROAR participants saw home care as “needed now” and noted that it will be even more crucial as they continue to age with CCD:

But I know that in time, I'm going to have other problems. I have chronic problems and they are going to get worse. And I am going to need further home care support services ... I think those supports – home care support services – are needed now for the elderly [sic]. (FG3, U, Indigenous Elder)

Along with growing older, transitions from the hospital to home were felt to require more support with one participant indicating that

There has to be more training of patients when they are going home after major surgery and ... you shouldn't have to get upset when you are trying to get better. To say, well I'm not ready to go home, I don't have anybody ... I don't know anybody, all my people I know are elderly [sic]. (FG, SR2)

Improved Transportation

Unsurprisingly, transportation was a major topic of conversation at all of the focus groups and interviews, regardless of the size of the participant's community or their proximity to an urban centre. Coordinating transportation with medical appointments was a concern for those living in rural or small rural towns as well as older adults in Kamloops. Participants noted they could not make appointments at walk-in or primary care clinics, yet trips with HandyDart (public transportation service for older adults and persons with disabilities) require advance booking. As a result of this and other factors, participants spoke of the inconvenience of having to rely on family, friends, and/or neighbours. The complexity or multi-faceted nature of transportation issues

found in this research (see Figure 1) related not only to older adults getting themselves to primary and community care in their own community or a neighbouring one, but also receiving home and community care from health care providers travelling in from an urban centre.

More Doctors, Knowledgeable Doctors, and 'Proper' Doctors

When all participating communities were asked about their top priorities for the repositioning work which Interior Health was undertaking, they highlighted the need for more doctors, especially in the surrounding rural communities. The difficulty recruiting doctors to practice in rural small towns was noted with a common complaint being that doctors will only commit to “a year, two years, they won't come for longer” (FG, SR3). This contributor to lack of continuity in primary care was upsetting for our participants, as suggested by this dialogue:

P1: And it seems we are always getting put to another doctor, you know. Instead of the doctor that is supposed to be our family doctor, the one you really want to see. You make an appointment and they give you an appointment and you're seeing someone else.

P2: Most of your appointment time is taken up updating them [doctors at the clinic] on things that you have said twenty times already. (FG2, SR1, Indigenous Elders)

A related concern was not knowing how long doctors were likely to stay:

Fifteen years ago ... there would be four doctors' names on the list at the medical clinic ... [now] we are lucky we have two. How long are they going to stay? We don't know, but for past history, they haven't stayed more than a couple of years. (FG, SR3)

Although recruiting and retaining doctors was an issue primarily for those living in rural communities, the need to rely on walk-in clinics was a concern expressed by both rural and urban residents. A rural participant described how “people are being referred to these walk-in clinics more and more” (FG1, SR1). Participants felt that having regular doctors would improve their continuity of care and expressed concerns with walk-in clinics: “The other concern would be with the walk-in clinics ... nobody knows your history ... the [family] doctor would know your history” (FG1, U). An Indigenous Elder spoke of the shortage of family doctors in Kamloops:

There’s lots of people – older people – that are walking around that don’t have doctors and it’s hard to get doctors in clinics as well. They [Interior Health] don’t even know what they need, they need more than just a [walk-in] clinic. (FG2, U)

Older adults also discussed the need for doctors who understand their aging-related health problems – that is, “My first [priority] was the doctors who understand seniors” (FG, SR3). The timeframe allocated for appointments – 15 minutes – was felt to be insufficient to allow doctors to properly attend to the needs of older adults, many of whom are living with CCD. “What are we concerned about? Quality care, I think, is what it comes down to. Not quantity care” (FG, SR4). ROAR participants not only spoke of doctors’ inability to address complexity: “He [doctor] doesn’t want to cover all the items. They only have a short period of time and you don’t always feel that you get your two of three things covered” (FG1, R2), but they also identified this as a key difference between doctors and nurse practitioners and linked this to the payment system: “Nurse practitioners get paid by the hour, not by the patient, [while] doctors get paid by the patient” (Int, SR1).

Although doctors were a top priority for the Indigenous and South Asian participants, they were seeking a particular type of doctor: knowledgeable doctors (Indigenous) and “proper” doctors (South Asian). As one Indigenous Elder stated, “There should be more First Nations in [primary care] as doctor and nurse, and the dentistry ... they seem to have other people, foreign people in there” (Int, R1, Indigenous Elder). Elders saw this as an important aspect of Indigenous peoples’ health care needs and highlighted that, “We need somebody that knows the plants” and “somebody who knows which plant helps one thing and which plant helps another one” (FG2, SR1).

Similarly, South Asian participants talked about “proper” doctors which denoted doctors who could speak the participants’ language and provide culturally appropriate care, which was seen to include “provid[ing]

some kind of home service” (FG4, U). When referring to those who spoke very little English and/or had communication impairments, one participant said, “That’s the problem, most of the people, they can’t talk good English, so they are looking for Punjabi doctors so they can communicate with them in their own language. So, that’s the big problem here” (FG4, U, South Asian older adult). One South Asian participant, advocating for more than one Punjabi doctor in Kamloops stated “we want proper doctors in this [walk-in] clinic” (FG4, U).

Playing an Active Role to Effect Change

When asked what they thought the health authority could do to ensure that older adults had input into Interior Health’s repositioning work, participants were enthusiastic about wanting to play an active role to effect change – by being consulted on the restructuring of health care services, for example. They valued the opportunity to share their views through the ROAR project and wanted to be involved in sharing ROAR findings, seeing this as aligned with their expressed “need for action, not a report” (FG, SR3).

Specific suggestions of how Interior Health could involve older adults, included providing them with information on repositioning and the “support” to be provided through this initiative, and creating an opportunity for “face-to-face” interaction with decision-makers, preferably in their home communities (i.e., rural and small rural towns). As one participant stated, “We’re expected to go to Kamloops, Kelowna, and to Victoria to express our needs. How about somebody comes to us for a change?” (FG, SR3). To better facilitate rural service-user involvement, ROAR participants suggested selecting two or three representatives per community to meet regularly – “every six months” – with Interior Health administrators. This would allow older adults to recommend changes to service delivery that might meet the needs of their specific rural town and decision-makers to determine if this could be transferable to other rural towns.

Playing an active role to effect change also refers to actions that Interior Health could take to improve home and community care for older adults. For example, one community expressed the need for housing and care options other than assisted living and residential care, something akin to “intermediate care”:

I don’t think they give enough time to some people when they need more care. Now there’s no intermediate care anywhere in the province, which I think is sadly needed for people. They’re not ready for end of life care, but they’re in-between [assisted living and residential care], and they need support. But they’re not getting any, because there isn’t any. (FG1, SR1)

One community that had formed a citizen-led health coalition was very critical of what they perceived to be a centralized or top-down approach by Interior Health, advocating for the formation of health boards and a bottom-up approach: “I don’t know what changes that Interior Health can do. They’ve got to start from the bottom and work up. See the mess that they’ve got” (FG2, SR3). Another participant from this community felt that a centralized approach prioritized finances over quality health care: “It might be a good financial management to centralize [health services], but it’s really crappy health care. So, if the accountants in the system are making the decisions, then the dollar comes first, not the patient” (FG1, SR3).

Co-location of health care services – “one-stop shopping” – was a desire expressed by several rural-dwelling Interior Health participants:

I think the one-stop shopping thing where you have all the information, you have communication about what’s going on in the medical system, that would affect you and elderly education, all sort of bundled into one, so that you could go to one place and have this ... I think [this] would take a huge load off senior care. (FG, R2)

This would alleviate the need to “go back and forth here and there” as one participant described, “especially for [Indigenous] Elders [who] don’t have enough energy to run all over the place” (Int, R1). Participants from another rural (small) town advocated for “a total health centre”, which they saw as naturally building upon their current setup: “Right across the street you got your health centre, up the street you have the doctor’s office, you can go downtown, I mean the setup that we have here in [rural small town] is perfect” (FG, SR4).

Not only did ROAR participants want to be directly involved in making change, but they also wanted the health care system to act upon their recommendations when consulting with them, whether this be through citizen-led health coalitions or service-user research projects such as ROAR.

Discussion

This research was motivated by a health restructuring initiative, known as repositioning, that Interior Health undertook. Older adults living in Kamloops and surrounding rural towns were unfamiliar with repositioning. We suspect this is not unique to the ROAR study, as rural older adults’ perspectives on aging are not often considered by policy-makers (Bascu et al., 2014) or aged care services (Petriwskyj et al., 2014). Despite Interior Health’s commitment to service-user involvement, evidenced by the creation of the Patient Voices Network,² it tends to be those living in urban centres (e.g., Kamloops

and Kelowna) who are consulted. Further, proximity to government has been found to be connected to better health service delivery for rural older adults (Bascu et al., 2014). Bechtel and Ness (2010) caution that lack of patient input into the redesign of services has the potential for users to fail to engage with the new services, and to view efforts to develop or restructure services unfavourably. This could be the reason why ROAR participants living in rural and small rural towns were more skeptical about Interior Health’s repositioning efforts than those living in the urban centre. This shows that decision-makers need to engage more with rural older adults to ensure that they are able to access the new services that result from their restructuring efforts.

Several of the policy interventions to support older adults to age in place in rural communities in Saskatchewan (Bascu et al. 2014) were consistent with priorities identified by ROAR participants, including better home care and improved transportation. Given the serious cuts to home and community care services in British Columbia from 2001 to 2017 (Longhurst, 2017), it is no surprise that ROAR research participants called for better home care when interviewed in 2016. This reduction in service was a political decision that differentially impacted older adults in British Columbia’s northern and interior regions. There is hope that the 2017 change in government will result in improvements in Elder care, including increased home support hours. The political-economic context in which repositioning began was one marked by neoliberal ideology and austerity measures; the tide appears to be turning as the government announced \$240 million to improve seniors care in fall 2018 (Office of the Premier, 2018).

Transportation is consistently identified as an issue for older adults living in rural communities (Averill, 2012; Keating et al., 2011; LaFortune et al., 2015), thus the ROAR study was no different in this respect except that transportation was an issue in the small city, as well as the rural and small rural towns. The concept of mobility as advanced by Webber, Porter, and Menec (2010) is inclusive of transportation, however it does not capture the issues identified in the ROAR study (see Figure 1) due to the authors’ lack of focus on rural aging. ROAR participants did not speak of walking or using mobility devices – the other components of mobility (Webber et al., 2010) – in relation to accessing primary and community care. This may be related to the average age (75 years) and type of CCD with which the ROAR sample were living with very few of our community-dwelling participants having mobility impairments. This is a limitation of our study inasmuch as those with mobility impairments may hold other views on repositioning.

With respect to participants’ desire for more doctors or nurse practitioners (NPs) – or increased access to

primary care providers, this echoes the recommendations in recent reports (Longhurst, 2017; Select Standing Committee on Health, 2017). The Select Standing Committee recognized that rural communities are under-resourced by health care professionals, including primary care providers like family doctors and family practice NPs. Rural-dwelling ROAR participants reported easier access to NPs than to family doctors and more continuity with the former than the latter. Thus, the Select Standing Committee's call for more generalist NP services in rural and remote communities fits with our findings. Primary care needs to be better integrated into home and community care in British Columbia (Longhurst, 2017), and interdisciplinary teams are recommended for rural areas (Select Standing Committee, 2017). This call for interdisciplinary teams not only acknowledges the challenges in recruiting family doctors to rural practice, but also the fact that NPs can serve as the primary care provider. Interprofessional practice could be accomplished through an integrated primary care model that includes intensive case management; for example, a model such as this was found to reduce hospitalizations for older adults in France (De Stampa et al., 2014). The College of Family Physicians of Canada and the BC College of Family Physicians' (2017) report card on the role of the British Columbia government in health care emphasizes that progress has been made in increasing "attachment" of patients to family physicians. Thus, there are now fewer people "walking around without doctors" as a ROAR participant referred to this "attachment" issue. However, the report card indicates there is still much more progress to be made and recommends the implementation of *patient medical homes*³ to further advance accessibility to primary care. Key features of both patient medical homes and integrated primary care models are interdisciplinary teams and system integration.

With respect to the call for "proper" doctors from South Asian participants and knowledgeable doctors from Indigenous Elders, several studies have recognized that challenges associated with culture, language, and economics require attention and action (Averill, 2012; Ferris, Glicksman, & Kleban, 2016; LaFortune et al., 2015). Ferris et al. (2016) found that those who experienced greater unmet needs related to home and community care were often racialized individuals, which points to the significance of SDOH. The use of "proper" and "knowledgeable" as coded ways of speaking of culturally appropriate and/or culturally safe care resonates with Brotman's (2003) finding that older minority ethnic and/or racialized women do not speak directly about "racism"; rather, they use "rudeness" to describe their experiences of discrimination. As older adults from equity-seeking groups may not specifically label the actions of health care providers as oppressive or

identify the health care system as discriminatory, it is incumbent upon critical gerontologists to pay attention to coded words like "proper" or "knowledgeable" as well as to the fact that the top priorities of older adults are largely systemic (better home care, improved transportation, and more doctors) and connected to SDOH, rather than individual health promoting strategies like self-management programs.

Many studies identify the need for coordinated, integrated, holistic care which refers to the way services complement or work together to improve care transitions, regardless of location. This is not the same as the co-location of services or "one stop-shopping" that rural ROAR participants identified as necessary. This vision of an integrated and coordinated approach to health care informed the development of the Seniors Health and Wellness Centre which was proposed as part of the repositioning initiative and opened after our study was completed. However, this service currently addresses the needs of a small proportion of the population in the urban area, and not those of rural-dwelling older adults. Further, older adults must be referred by a primary care clinician and the waiting list could delay access.

ROAR provided a research-based platform for older adults – both urban- and rural-dwelling – to share their views on Interior Health's repositioning of primary and community care. The desire of ROAR participants to play an active role in health care restructuring confirms findings of previous client engagement studies (Basco et al., 2014; Grimmer et al., 2015; Petriwskyj et al., 2014). This also lends support for positioning older adults as "experts or consumers", and "diverse in their needs and wishes", rather than "disempowered" or "resistant or non-compliant", as in Petriwskyj et al.'s (2014) typology of the ways that clients are framed in aged care services (see Literature Review section). The ROAR study demonstrates not only the need for increased engagement of rural-dwelling older adults in the restructuring of primary and community care, but also that it is possible to do so through viewing them as experts with diverse needs, consistent with a critical gerontological perspective.

Implications

Findings from this study led to a funded knowledge translation project (in progress) aimed at creating knowledge translation tools and a forum for older adults to discuss, with decision-makers and knowledge users, ways to move ROAR findings into practice. Not only does research need to include diverse service users, but older adults also need to be fully included in the implementation of new and improved health care services (e.g., Seniors' Health and Wellness Centre, patient medical homes, new primary care health providers), including the marketing of these services. Given that resources

are finite, a new approach needs to address access to primary care in rural communities, one that does not reflect a “cookie cutter approach”. A cultural shift in health care is necessary to actively engage care recipients in service model development. Research is needed on the extent to which the outcome of repositioning (the Seniors’ Health and Wellness Centre) addresses SDOH and meets the needs of rural communities.

While Interior Health embarks on the process of redesigning and restructuring community health care services, it is important to consider the impact of the process on the system’s end user – the patient and their family members. In a system where support for and encouragement of patient self-management is a priority, encouraging and welcoming patient input into the restructuring of health care services facilitates this goal. Writing on behalf of the Institute for Healthcare Improvement (IHI), Feeley (2015) identified the need to “change the balance of power” by collaborating directly with patients and family members. By applying this to the design of programs and services, Feeley (2015) demonstrated how health care could be developed and delivered in a way that is meaningful, relevant, and engaging to service users. Creating a culture of service user participation in health care self-management and health care service planning and redesign would enable older adults to play an active role to effect change and be viewed not only as service users, but also as experts.

Notes

- 1 The new word is “transformation” (Lori Seeley, personal communication, February 5, 2018).
- 2 Patient Voices Network (<https://patientvoicesbc.ca>) was created to bring together patients from across British Columbia to share their experiences and effect changes in primary care.
- 3 A “patient medical home” is a team-based family practice that consists of physicians and other health care providers working together to provide integrated care in a specific geographic area.

References

- Allan, D., & Cloutier-Fisher, D. (2006). Health service utilization among older adults in British Columbia: Making sense of geography. *Canadian Journal on Aging*, 25(2), 219–232.
- Averill, J. (2012). Priorities for action in a rural older adults study. *Family and Community Health*, 35(4), 358–372.
- Baker, S. E., & Edwards, R. (2012). *How many qualitative interviews is enough? Expert voices and early career reflections on sampling and cases in qualitative research*. National Centre for Research Methods Review Paper. Southampton, ENG: National Centre for Research Methods. Retrieved from http://eprints.ncrm.ac.uk/2273/4/how_many_interviews.pdf
- Bascu, J., Jeffery, B., Novik, N., Abonyi, S., Oosman, S., Johnson, S., & Martz, D. (2014). Policy, community, and kin: Interventions that support healthy rural aging. *Activities, Adaptation, & Aging*, 38(2), 138–155.
- Bazeley, P., & Jackson, K. (2013). *Qualitative analysis with NVivo* (2nd ed.). Los Angeles, CA: Sage.
- Bechtel & Ness. (2010). If you build it, will they come? Designing truly patient-centered health care. *Health Affairs*, 29, 914–920.
- Berg, B. L. (2004). *Qualitative research methods for the social sciences* (5th ed.). Boston, MA: Pearson Education.
- BC Stats, Ministry of Jobs, Trade and Technology. (2018). *British Columbia population projections 2016–2041*. Retrieved from <https://www2.gov.bc.ca/gov/content/data/statistics/people-population-community/population/population-projections>
- Bradshaw, C., Atkinson, S., & Doody, O. (2017). Employing a qualitative description approach in health care research. *Global Qualitative Nursing Research*, 4, 1–8.
- Brotman, S. (2003). The limits of multiculturalism in elder care services. *Journal of Aging Studies*, 17, 209–229.
- Cohen, M. (2012). *Caring for BC’s aging population: Improving health care for all*. Vancouver, BC: Canadian Centre for Policy Alternatives – BC Office. Retrieved from <https://www.policyalternatives.ca/sites/default/files/uploads/publications/BC%20Office/2012/07/CCPABC-Caring-BC-Aging-Pop.pdf>
- College of Family Physicians of Canada and the BC College of Family Physicians. (2017, May). *The role of the British Columbia government in health care report card*. Retrieved from http://bccfp.bc.ca/wp-content/uploads/2017/05/CFPC_BCReportCard.pdf
- Davenport, J., Rathwell, T., & Rosenberg, M. (2005). Service provision for seniors: Challenges for communities in Atlantic Canada. *Longwoods Review*, 3(3), 9–16.
- De Stampa, M., Vedel, I., Buyck, J-F., Lapointe, L., Bergman, H., Beland, F., & Ankri, J. (2014). Impact on hospital admissions of an integrated primary care model for very frail elderly patients. *Archives of Gerontology and Geriatrics*, 58(3), 350–355.
- Estes, C., Biggs, S., & Phillipson, C. (2003). *Social theory, social policy and ageing: A critical introduction: Critical perspectives*. Maidenhead, ENG: Open University Press.
- Funk, L. (2016). *Sociological perspectives on aging*. Don Mills, ON: Oxford University Press.
- Grimmer, K., Kay, D., Foot, J., & Pastakia, K. (2015). Consumer views about aging-in-place. *Clinical Interventions in Aging*, 10, 1803–1311.

- Hanlon, N., & Halseth, G. (2005). The greying of resource communities in northern British Columbia: Implications for health care delivery in already-underserved communities. *The Canadian Geographer/Le Géographe canadien*, 49(1), 1–24.
- Hanlon, N., Rosenberg, M., & Clasby, R. (2007). Offloading social care responsibilities: Recent experiences of local voluntary organisations in a remote urban centre in British Columbia, Canada. *Health & Social Care in the Community*, 15(4), 343–351.
- Hulko, W., Brotman, S. & Ferrer, I. (2017). Counter-storytelling: Anti-oppression social work with older adults. In Baines, D. (Ed.), *Doing anti-oppressive practice: Social justice social work* (3rd ed.) (pp. 193-211). Halifax, NS: Fernwood Publishing.
- Hulko, W., Stern, L., Brotman, S., & Ferrer, I. (2020). *Gerontological social work in action: Anti oppressive practice with older adults, their families, and communities*. Abingdon, UK: Routledge Press.
- Hsieh, H.-F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, 15(9), 1277–1288.
- Interior Health. (2014). *Local health area profile*. Kamloops, BC: Interior Health.
- Feeley, D. (2015, October 1). *Changing the balance of power: Applying radical redesign principles beyond patient care*. http://www.ihl.org/communities/blogs/_layouts/15/ihl/community/blog/itemview.aspx?List=81ca4a47-4ccd-4e9e-89d9-14d88ec59e8d&ID=75
- Ferris, R. E., Glicksman, A., & Kleban, M. H. (2016). Environmental predictors of unmet home-and community-based service needs of older adults. *Journal of Applied Gerontology*, 35(2), 179-208.
- Keating, N., Swindle, J., & Fletcher, S. (2011). Aging in rural Canada: A retrospective review. *Canadian Journal on Aging*, 30(3), 323–338.
- Krueger, R. A., & Casey, M.-A. (2000). *Focus groups: A practical guide for applied research* (3rd ed.). Thousand Oaks, CA: Sage.
- Lafortune, C., Huson, K., Santi, S., & Stolee, P. (2015). Community-based primary health care for older adults: A qualitative study of the perceptions of clients, caregivers and health care providers. *BioMed Central Geriatrics*, 15(57), 1–11.
- Longhurst, A. (2017, March). *Privatization and declining access to BC seniors' care: An urgent call for policy change*. Vancouver, BC: Canadian Centre for Policy Alternatives BC Office.
- Melnyk, B. Mazurek, & Fineout-Overholt, E. (2015). *Evidence-based practice in Nursing and Healthcare* (3rd ed.). Philadelphia, PA: Wolters Kluwer.
- Ministry of Health. (2015a). *2015/2016 Health Mandate Letter*. Victoria, BC: Ministry of Health.
- Ministry of Health. (2015b). *Rural health services in BC: A policy framework to provide a system of quality care: Cross sector policy discussion paper*. Victoria, BC: Author. Retrieved from https://www.health.gov.bc.ca/library/publications/year/2015_a/rural-health-policy-paper.pdf
- Office of the Premier. (2018, September 25). *B.C. seniors to get the hours of care they need as funding and staffing increased*. Retrieved from <https://news.gov.bc.ca/releases/2018PREM0072-001861>
- Petriwskyj, A., Gibson, A., & Webby, G. (2014). Participation and power in care: Exploring the “client” in client engagement. *Journal of Aging Studies*, 31, 119–131. <http://dx.doi.org/10.1016/j.jaging.2014.09.007>
- Raphael, D. (Ed.). (2009). *Social determinants of health* (2nd ed.). Toronto, ON: Canadian Scholars' Press.
- Ryser, L., & Halseth, G. (2011). Informal support networks of low-income senior women living alone: Evidence from Fort St. John, BC. *Journal of Women & Aging*, 23(3), 185–202.
- Select Standing Committee on Health. (2017). *Looking forward: Improving rural health care, primary care, and addiction recovery programs*. Victoria, BC: Legislative Assembly, Province of British Columbia.
- Skinner, M. W., Rosenberg, M. W., Lovell, S. A., Dunn, J. R., Everitt, J. C., Hanlon, N. H., & Rathwell, T. A. (2008). Services for seniors in small-town Canada: The paradox of community. *Canadian Journal of Nursing Research*, 40(1), 80–101.
- Spoorenberg, S. L. W., Wynia, K., Fokkens, A. S., Slotman, K., Kremer, H. P. H., & Reijneveld, S. A. (2015). Experiences of community-living older adults receiving integrated care based on the chronic care model: A qualitative study. *PLoS ONE*, 10(10), 1–21.
- Webber, S. C., Porter, M. M., & Menec, V. H. (2010). Mobility in older adults: A comprehensive framework. *Gerontologist*, 50(4), 443–450.
- World Health Organization. (2013, May 7). Social determinants of health. Retrieved from www.who.int/social_determinants/en

Appendix 1: ROAR Interview Guide

In being an older adult and thinking about health services in your community,

1. How well do primary and community care meet your needs as an older adult?
 - a. What is working well?
 - b. What is not working well?

2. What have you heard about the repositioning work that Interior Health is doing?

[If participants reply "nothing" or talk about "rehousing" or something else unrelated, then describe repositioning in primary and community care as:

The restructuring of community services to provide comprehensive and holistic care to adults aged 75 and older, primarily with complex chronic conditions. Repositioning refers to the shift of resources within the healthcare system from acute care settings to support independent living at home or in the community, with the goal of reducing hospital and residential care admissions.]

3. How will this repositioning impact you and [insert name of community]?
- a. How might this help older adults with multiple chronic health conditions?

- b. We are interested in the social factors we asked you about earlier [in the socio-demographic questionnaire] (e.g., age, gender, Indigenous ancestry, ethno-cultural background, income, and living situation). How might the repositioning address these factors? What about your situation in particular?
4. What could the health authority do to make sure older adults have input into this repositioning?
- a. How do you like to give input (e.g., community forum, letter, e-mail, phone call)?
5. Name your top two priorities to improve health care for older adults.
6. Is there anything else you can tell us to help us understand older adults' views on repositioning?