



2021

## The experiences of rural British Columbians accessing surgical and obstetrical care

Aria Jazdarehee

*University of British Columbia Faculty of Medicine, [aria.jaz@alumni.ubc.ca](mailto:aria.jaz@alumni.ubc.ca)*

Anshu Parajulee

*University of British Columbia, [anshu.parajulee@ubc.ca](mailto:anshu.parajulee@ubc.ca)*

Jude Kornelsen

*University of British Columbia Department of Family Practice, [jude.kornelsen@familymed.ubc.ca](mailto:jude.kornelsen@familymed.ubc.ca)*

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### Recommended Citation

Jazdarehee, Aria; Parajulee, Anshu; and Kornelsen, Jude (2021) "The experiences of rural British Columbians accessing surgical and obstetrical care," *Patient Experience Journal*: Vol. 8 : Iss. 1 , Article 15. DOI: [10.35680/2372-0247.1505](https://doi.org/10.35680/2372-0247.1505)

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### Cover Page Footnote

The authors would like to express extreme gratitude to our funders, BC's Joint Standing Committee on Rural Issues and the Rural Coordination of BC and to acknowledge the participants who shared their experiences. Additionally, we thank Eva Sullivan for her editorial support, Jessica Schaub for assistance with figure development, and members of the Centre for Rural Health Research for their support in data processing. This article is associated with the Policy & Measurement lens of The Beryl Institute Experience Framework (<https://www.theberylinstitute.org/ExperienceFramework>). You can access other resources related to this lens including additional PXJ articles here: [http://bit.ly/PX\\_PolicyMeasure](http://bit.ly/PX_PolicyMeasure)

# The experiences of rural British Columbians accessing surgical and obstetrical care

Aria Jazdarehee, *University of British Columbia Faculty of Medicine, ariajaz@student.ubc.ca*

Anshu Parajulee, *University of British Columbia, anshu.parajulee@ubc.ca*

Jude Kornelsen, *University of British Columbia Department of Family Practice, jude.kornelsen@familymed.ubc.ca*

## Abstract

The attrition of small volume surgical and maternity services in rural Canada over the past three decades has made access to these services especially challenging for rural citizens. While many of these closures have occurred as consequences of regionalization, a strategy to regionally centralize healthcare services, many studies investigating outcomes of regionalization have focused on costs and medical endpoints rather than the direct experiences of the rural patients affected. In this study, we aimed to understand and document the experiences of rural residents accessing procedural and maternity care both locally and away from home. This study is part of a larger evaluation framework which prioritizes the insight of rural residents regarding healthcare issues. We conducted focus groups and interviews with 54 participants in six communities across British Columbia's southeastern and northern regions. Thematic analysis showed that rural residents experienced unique challenges when leaving their communities to access care. This included logistics of travel, poor coordination of care between multiple providers, and financial and psychosocial issues. Despite being mostly content with the medical care received, participants expressed needing more attention to their unique needs and preferences as patients leaving their home communities for care. Understanding these challenges facilitates the planning of healthcare services in a more equitable manner. Our findings suggest that we need increased patient-centered healthcare planning that aims to alleviate the financial and psychosocial strain on rural residents.

## Keywords

Rural health services, rural health inequities, patient experiences, patient-centered care, health services accessibility, patient satisfaction

## Introduction

Over the past three decades, many rural communities in British Columbia (BC) and elsewhere in Canada have experienced the attrition of small volume surgical and maternity services.<sup>1,2</sup> Canada's healthcare system is publicly funded and provides free point-of-care hospital and medical services to Canadians.<sup>3</sup> Though national standards are set, this system is governed at the provincial level, and these closures have primarily been part of provincial strategies to 'regionalize' healthcare whereby acute care services are redistributed away from rural hospitals to larger regional centers.<sup>4</sup> Intended primarily to increase efficiencies, reduce costs of healthcare through consolidation of hospital services, and improve access to specialist care, regionalization aims to decentralize the management of healthcare services from provincial authorities to smaller regional boards, in order to better serve the members of the communities they serve.<sup>5</sup> However, regionalization has inadvertently led to the closure of many small rural sites due to regional centralization of resources.

Studies investigating the outcomes of regionalization in Canada have primarily focused on costs and health outcomes and have largely not considered the impacts on experiences of care for patients. This is despite BC's Patient-Centered Care Framework, which deems the needs of patients and families, including those living rurally, central to the design of the province's healthcare system.<sup>6</sup> The few studies that focus on the experiences of patients leaving their communities for care have focused on patients from a specific community or with a specific medical condition. A study on experiences of rural cancer patients from Northern BC found distance and travel logistics to be key challenges in accessing medical care.<sup>7</sup> Additional barriers reported by patients in other studies include the financial burden of transport, the social implications of depending on a travel companion, and the physical discomfort of commuting long distances with pre-existing medical conditions.<sup>8-11</sup> The experience of leaving one's community for care is often characterized by stress and anxiety for patients, especially among those lacking social support.<sup>7,9,12,13</sup> A true understanding of the constriction of rural care requires an analysis of not only

healthcare costs and patient health outcomes, but also the psychosocial and financial impacts to families and communities.<sup>14,15</sup>

Studies have shown poorer health, higher burden of preventable disease, and higher mortality rates in those living in rural and remote settings, as compared to urban communities.<sup>16,17</sup> Even though these disparities are well-documented, rural residents are not as well served and have greater difficulty in accessing medical services compared to urban residents.<sup>18</sup> In this present study, we aim to understand the experiences of rural residents with diverse medical backgrounds from six communities in accessing surgical and obstetrical care both locally and away from home. We will first describe experiences with services in their home community, and then explore the direct and indirect costs for patients when accessing services away from home. By understanding the challenges faced by rural residents in accessing care, we are better able to plan and deliver healthcare services in a more equitable manner which is person- and family-centered. As many rural communities continue to face the risk of closure of health services, such person-centered planning

will help reduce barriers faced by rural residents in accessing care and ultimately reduce the disparities in health between rural residents and their urban counterparts.

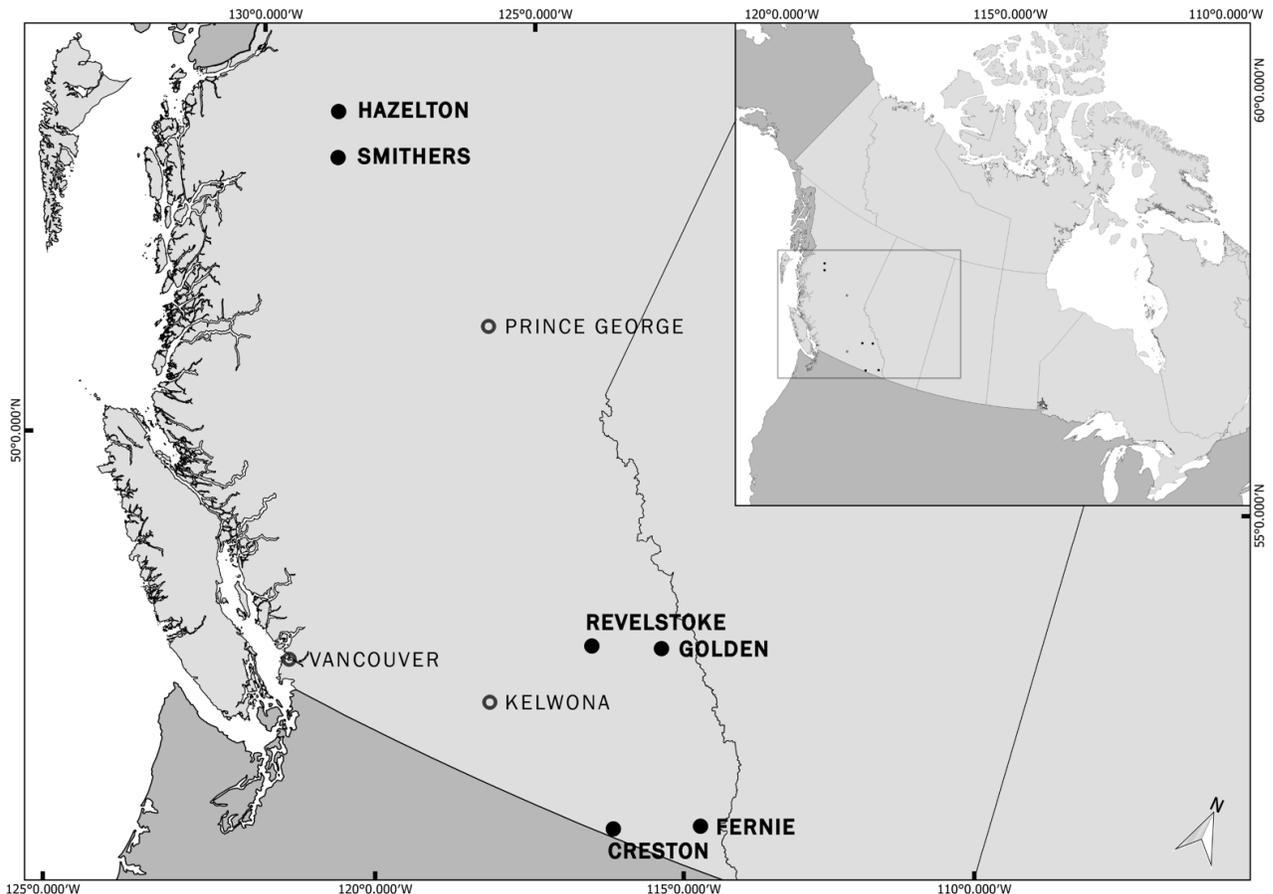
## Materials and Methods

### *Setting and Sampling*

This study is part of the evaluation of the Rural Surgical Obstetrical Networks (RSON) initiative, which supports safe surgical and obstetrical care closer to home for seven rural communities in BC. RSON, funded by the Joint Standing Committee on Rural Issues (a BC Ministry of Health and Doctors of BC Committee), aims to enhance the availability and stability of rural and remote health services. The following RSON communities participated in this study: Creston, Golden, Fernie, Revelstoke, Smithers, and Hazelton (Figure 1).

These communities have a mean population of 5600 (range 3700-7550) and fall within the Interior Health and Northern Health Authority jurisdictions, which serve BC's southeastern and northern regions, respectively. These

**Figure 1. Map of British Columbia, Canada (participating communities are bolded)**



regions typically experience long, cold winters with heavy snowfall. Road conditions in the winter are often hazardous, and road closure due to adverse weather is common. All participating communities have hospitals offering 24/7 emergency and maternity care. All offer more limited procedural care.

### ***Focus Groups and Interviews***

Between January–November 2019, we facilitated focus groups and interviews with surgical and maternity patients as well as family members from six rural communities. The study team developed an interview guide based on previous qualitative research findings on experiences of care among rural patients.<sup>19</sup> Participants who were not available to attend focus groups were invited to participate in an in-person or telephone individual interview. Focus groups lasted 60–90 minutes and interviews lasted 30–60 minutes. Focus groups and interviews were largely unstructured as we used open-ended probing questions. The study team continued to interview participants until theoretical saturation was reached, that is, no new topics emerged during interviews. With permission from participants, interviews and focus groups were audio recorded and transcribed verbatim. All transcripts were reviewed against audio files to ensure transcription accuracy.

### ***Data Analysis***

To analyze the interview and focus group data, thematic analysis was undertaken as it provided a pragmatic approach to the data and ensured simplicity for communication with patients and practitioners.<sup>20,21</sup> Two members (AJ,AP) reviewed all transcripts, independently developed preliminary codebooks which were compared to ensure semantic congruency, then applied a consensus codebook to an additional transcript. One team member (AJ) used the final codebook to code all transcripts, then analyzed the coded data to yield themes. Transcripts were coded using NVivo software (version 12). Following completion of the analysis, results of the study were shared with participants through a written report and an online webinar.

### ***Ethical Approval***

This study received harmonized ethical approval by the Behavioural Research Ethics Board at the University of British Columbia and the research ethics committees at the BC Health Authorities where this study took place (UBC Certificate Number H18-01940).

## **Results**

A total of 54 patients participated in the study. Eight were interviewed individually and 46 participated in focus groups. Participants provided narratives regarding their experiences accessing care in both their local communities

and away from home. Seven main themes emerged, each discussed in detail below.

### ***Experiences with Local Care***

Participants shared their recent experiences accessing maternity and low acuity surgical care in local rural hospitals. The majority of participants were satisfied with the care they received, noting the dedication of their local care teams to provide quality care despite perceived limitations in resources. Patients exhibited high levels of confidence in their care providers' abilities and expressed support for increased local low-acuity surgical capacity. As one patient noted, "We have a lot of capable doctors, ... I just feel like the doctors don't have their tools." Participants described the efficiency and convenience of local access to surgery, including not having to endure long commutes in potentially dangerous road conditions.

Referring specifically to maternity care, women expressed satisfaction with the care received but also desired increased options for type of provider and location of delivery, within the context of giving birth 'closer to home.' There was strong desire to maintain or add midwifery and doula care. In reference to midwifery care, one participant noted:

"I would say it's the best birthing care you can get, you know. Because the appointments are 30 minutes instead of 15. And the after care, [the midwife] came to my house to weigh the baby, and we had tea and it was nice... I feel that it was comfortable [and a] nurturing level of care."

The stories shared by participants also illustrated perceived insufficiencies of the local services provided. In addition to the reported lack of primary care physicians, several participants described their local hospitals as being understaffed and under-resourced. Many patients reported long wait times in hospital which they thought was due, in part, to insufficient access to primary care, resulting in increased visits to the emergency room for non-urgent reasons such as prescription refills.

Despite these limitations in resources and staffing, participants described numerous instances in which they thought local staff went above and beyond to address their needs. One participant had surgical staples removed on Christmas Eve by his family doctor, saving him from driving hours to have them removed by his surgeon. Another had his doctor accompany him on a long ambulance ride to another community in case issues arose along the way. Participants also described programs to meet community needs locally, such as visiting specialists and telehealth consultations.

"...The video link was perfect because it meant I could speak to the oncologist in charge of my care and ask her any questions that I could. There was no rushing, it was a private room, and I took my husband with me. We sat and

we made a whole list of questions and...so that saved me a huge amount of anguish of travelling.”

### **Transportation**

Participants appreciated that certain conditions could not be handled locally and would require travel away from their community. Patients travelled by air or ground ambulance in emergency situations, and personal vehicles or ferry in non-emergency situations. The main issue voiced by participants in each community was the danger of travelling through unpredictable road and weather conditions. Multiple participants shared stories of driving through snowstorms and washed-out road lines, as well as experiencing near accidents and frequent closures.

“The road...is never cleared or it’s icy. It becomes so bad. People are killed in the winter.”

These conditions triggered stress and anxiety in many patients, as one participant described:

“We have a very high anxiety around travelling even in the summer on the highway and so it’s...I do not sleep the night before we have to drive and then I can’t drive because I haven’t slept.”

Several participants noted that the hazardous conditions have been enough of a deterrent to keep them from accessing care on at least one occasion. Participants raised other issues including long travel times, physical discomfort, limited cell service on the way, and the stress of navigating unfamiliar communities. Participants described travelling with companions, usually friends or family members, to provide emotional support or assistance driving. Travelling with companions required additional logistical preparations including coordinating time off work together. Some participants felt guilty about being a “burden” on companions who helped.

In emergency situations, participants were transported by air or ground ambulance after coordination by local staff. Of those transported, many expressed satisfaction with the availability and efficiency of the transportation provided. Several noted the supportive staff who comforted them along the way.

Others shared less positive experiences of ambulance transport. One patient was transferred three times in different ambulances due to jurisdictional boundaries before reaching her destination. A prominent concern was the one-way nature of ambulance transport, which left patients having to rely on family or friends for rides home.

Many elderly participants described significant challenges around travel, as many could either not travel independently or drive the long distances required. Participants did mention supports available to those requiring assistance, including bus services and community

shuttles, but these operated infrequently and on limited schedules. One participant described, “When we came here 13 years ago, we didn’t even mind driving to [referral community]. Like it wasn’t even an issue, but the issue becomes as you age and as your health deteriorates. And we are finding that we are at the point where it’s extremely difficult.”

### **Experiences with Care Away from Home**

Participants in this study travelled out-of-town for high-acuity and specialized services, which ranged from computerized tomography (CT) imaging to brain surgery. Many shared positive experiences receiving care away from home, citing the efficiency in which care was provided and expressing confidence in the knowledge and abilities of the healthcare workers. Delivering mothers were also generally satisfied with the care they received in referral centers. Stories were shared of ‘very friendly, knowledgeable nurses’ and care providers that comforted patients. One mother acknowledged the importance of having specialists on-site:

“I had [my son] in [referral community] with a midwife. Which I’m so grateful [for] because the birth happened very quickly, and the baby came out blue. And a team came [immediately] and brought him [back]...And from that point forward, he’s been healthy.”

There were also concerns with care received in referral communities, however. Many participants experienced difficulty scheduling appointments at times convenient for them, and others experienced staff in referral centers not being considerate of the unique challenges rural patients face in accessing care out of town:

“I had a hip replacement out of [referral community], and I said to the surgeon, ‘Well, do I really have to come all the way over here to have the staples out?’ And he said, ‘It’s up to you.’ But he said, ‘If you don’t, I won’t do your other hip.’”

Another issue stressed by participants in four communities was the perceived lack of adequate postoperative care in referral centers following surgery. Participants identified inadequate pain management, trouble mobilizing, and concomitant uncomfortable travel home resulting from their early discharge. As one participant shared,

“[Health Authority] needs to allocate more money for aftercare. You can’t just send us to [referral community]...and as soon as we breathe and open our eyes, send us home. And I’ve been in the hospital a lot in the last number of years. And the word always is ‘go home and if there’s a problem go to your emergency.’ That’s not really good practice.”

### ***Organization and Delivery of Healthcare: Challenges for Rural Residents***

Although participants were generally satisfied with the quality of care received in referral sites, they recounted hardships preceding and following this care. The four main issues that emerged from the discussions were early discharge following surgery, gaps in communication between providers and patients, amount of travel required for pre- and post-surgical visits, and interprovincial barriers in accessing care.

As mentioned above, many participants thought they were discharged from referral sites without sufficient post-surgical care or adequate time to recover before enduring a long journey home. Seven participants attributed this to the high demand experienced by referral care sites to care for the many patients flowing in from surrounding communities.

“Go to [referral community], they’re at 130% capacity every time I’m there. Why are we regionalized [there] when they can’t accommodate us?”

Another problem participants identified, which made the early discharge more difficult to manage, was the lack of assistance to travel home. Many participants relied on friends or family for rides back home, and those who had driven others spoke of the difficulties in managing patients during the early phase of their recovery. One participant shared that she picked up her husband when “he couldn’t even talk,” and another described having to stop at the first rest stop because sitting in a moving car was too difficult for her husband. Another participant, without any friends or family to take her back home, had to be readmitted by the doctor in the referral care community just so she could be transported home. Not all participants thought that the healthcare system was responsible for providing return transportation, yet many thought more guidance and support could be provided to those transported out-of-town:

“Nobody told me to take a driver’s licence or anything with me so I could come home. I did know enough to take some clothes, but when you get to these places, as soon as they’re finished with you, you’re out. You’re on the doorstep. Nobody tells patients those things.”

Participants shared other instances of not receiving information on travel-related supports and resources. Many participants noted they were not previously informed of financial supports, such as tax incentives to reclaim travel costs. Others expressed that they were not guided towards available mental health and transportation resources. As such, participants desired expanded social worker and patient navigator services to better guide patients through the journey of leaving their communities to access care.

Participants also experienced gaps in communication between healthcare workers, leading to a break in continuity of care. Four participants explained that their local physicians did not receive documentation related to the care they received out-of-town. For some, this resulted in necessary follow-up appointments not being scheduled or organized. After her surgery, one participant shared,

“Yeah [my local physician] had no idea. She had no idea who did it, what was done, what the follow up’s going to be.”

The third thematic issue participants identified was the requirement to make long trips out of town for pre- and post-surgical appointments. They voiced that these trips require significant time and resources and wondered if all of these appointments need to occur in a referral center. One participant shared that she recently skipped a follow-up visit because she felt the cost of travel outweighed the benefit of care. Another shared,

“You have to go down there because the anesthetist has to listen to your heart and your chest eight minutes tops, and I’ll be out of there. It’s a six-hour drive.”

There was an understanding by participants that some appointments in referral care sites are medically necessary, but many felt local visits would suffice in certain scenarios. For example, a participant shared that she travelled hours to spend six minutes filling a paper questionnaire in her surgeon’s office. Many participants thought that more care could be administered locally if local and referral care teams worked together to determine whether out-of-town visits are medically necessary. One participant expressed her satisfaction with an intermediate solution: follow-up visits in a community closer to her than the referral site.

Finally, difficulties in accessing care inter-provincially due to jurisdictional regulations was an issue brought up by participants in southeastern BC living close to the Alberta border. Multiple participants in these communities voiced that these regulations, which make accessing care in Alberta more difficult, “don’t consider [patients] on the east side of the province” and this often results in patients travelling longer distances to access care within BC. One participant shared that her father’s physician recommended that she write to her local elected official to advocate for closer cardiac care for her father in Alberta.

Participants shared how they had to be proactive in their own care in order to address some of the barriers and inefficiencies listed above. This included following up on delayed referrals or pushing for local follow-up options. This demonstrates a ‘cost’ imposed on patients, specifically of their time and effort. Other costs - financial and psychosocial - are described next.

### **Financial Costs**

Participants identified many types of financial costs required for travelling outside of their community for care, both direct and indirect. Direct out-of-pocket expenses included both travel costs, such as fuel and car maintenance, and living costs, such as accommodation and meals while in the referral community. Other costs such as childcare were related to covering responsibilities while away from home. For those who had received emergency transport to the referral community, the cost of a car rental, taxi, or flight home was substantial. Additionally, travelling with a companion contributed to increased overall costs. Accumulated high costs of hospital parking was an issue brought up by several participants as well.

Participants also described indirect costs and losses resulting from their travels. The main loss was due to time taken off work. Some participants used sick or vacation days whereas others were forced to take unpaid time off.

“I’m lucky that I still get paid on my sick leave, I’m very, very lucky or else that would’ve been a very big problem.”

For the participants in this study, financial costs were not prohibitive enough to render care inaccessible, yet several shared stories of others who could not afford to leave their community for care. Participants in one community described an elderly individual who could not access specialist care for his diabetes because the travel costs for regular appointments were too high. Others shared a story of going to a garage sale for a family selling their belongings to cover travel costs for cancer treatment.

To assist with the costs of travel, participants described accessing supports provided by their friends and families, communities, and government. Many participants stayed at a friend or family’s house while in the referral community. Several had some of their travel related costs covered by family members. For some, the presence of family support influenced the decision on where to access care:

“[If] I would have had to stay in [referral community] for the duration of my [stay], which would have been more expensive, I wouldn’t have had my family, friends or anyone there, so it would have made a huge difference to my mental wellbeing.”

Participants described that community-based supports were available to provide assistance with aspects of out-of-town care such as housing and transport. Several participants described community members coming together to assist patients in need by offering rides and financial support or organizing fundraisers. Participants also described governmental supports to help cover costs, such as tax credits, but noted that these often only covered

a small portion of costs and required a certain threshold or financial status to be eligible.

### **Psychosocial Costs**

Participants also highlighted health and social costs related to travelling for care, the main cost being not accessing care altogether due to barriers. Participants shared instances of having to cancel appointments due to hazardous weather conditions, and others simply chose not to access care because they thought the costs outweighed the medical benefits. Participants in every community described feelings of stress or anxiety when coordinating and undertaking travel to another community for care or physically being away from home. Some described the stress of navigating in a new community, and one participant shared, “...I’m in my 70s and I’m not comfortable staying in a motel room by myself.”

The narratives shared also highlighted several social impacts. Many noted the difficulty of being away from friends and family, and mothers particularly expressed the difficulty of being away from their families while receiving maternity care away from home. The need to travel also interfered with work and responsibilities at home. As one family shared,

“We live on a [working] farm. We can’t leave the farm with no one here. So, it makes it difficult when we have to do these trips.”

Many participants accepted that the need to travel for some care was a reality of rural living. For the participants in this study, attachment to their rural communities outweighed the burden of having to travel for care. As one participant shared, “when you’re forced to choose between some places that you love and [moving] someplace out of necessity, sometimes love beats necessity.” Many mothers, as well, expressed a strong desire for births to be close to home. As one mother voiced, “I was born and raised here and there was something in me that was like ‘I want my children to be born [here].’” Several participants described the difficulty of regularly having to leave their community to access care. One elderly participant shared that her doctor recommended she move to a larger town. Though the participants in this study were usually able to overcome barriers and difficulties in accessing care, this is not the reality for everyone:

“He moved out of town and the reason he gave is that he needed to be closer to medical care, so [he was]...moving and tearing himself out of a community that loves him dearly and I’m sure he does as well. So...there are some situations like that where people...do have to move.”

### **Suggestions and Support for Change**

Participants in every community expressed support for increased scope of low-acuity surgery in their local facilities. As one participant voiced, “There [are more]

things that could be done here. There's...three operating rooms in this hospital?" Many suggested that increased local surgical capacity would reduce the demand on referral site facilities, allowing the specialized staff there to focus on higher-acuity cases. Additionally, participants thought that more local services, in addition to increased telehealth and visiting specialist options, would mean less frequent medical trips out of town. Some argued this would better allow them to cope physically, mentally, and financially for the emergency situations when they would have to travel.

When accessing care outside their communities, participants suggested improved communication between local and referral care teams in order to ensure adequate continuity of care. Several also advocated for increased assistance with coordinating care. Many recommended reserving specific appointment times for out-of-town patients, which would allow patients to coordinate multiple appointments in a single day and avoid overnight stays in referral communities.

"Just look at the distance. If we can be booked for 10am in the morning instead of 7am in the morning you know? That would certainly help."

One of the main issues participants discussed was the lack of transportation following care, and some suggested implementing systems to provide transportation directly from the referral sites. Many desired increased supports for seniors who faced difficulties returning on their own due to limited access to resources and social support. Others suggested that simply improving awareness of available resources would have a big impact on accessing care.

Participants also expressed support for easier access to care out-of-province when these services are closer geographically, particularly in emergency situations:

"I just think geographically we're way closer to Alberta and their facilities than we are to anything else here. ...I get politics and things like that but when its life or death it shouldn't matter. It should be get[ting] this person to the closest facility that'll take care of them."

Participants expressed the need for care that incorporates mental health needs, particularly for those receiving care in an unfamiliar community. Many shared stories of emotional and psychological needs not being met, and others shared encounters with unsympathetic staff.

"I think there should be more nurses with psychological background or social workers...If someone had spoken to me...just [somebody] talking to you at the right time can really alleviate a lot of stress."

Altogether, the suggestions made by participants reflect the desire for an increased *person-centered* approach to the delivery of healthcare, easing the burden on rural residents when accessing care.

## Discussion

Our findings indicate that participants were satisfied with the medical and surgical care received, but often felt a lack of support surrounding the non-procedural aspects of care when receiving care away from home. Challenges included early release from hospital following surgery and difficulties accessing follow-up visits. To overcome these obstacles, participants had to rely heavily on financial or social capital.

Howard *et al.* similarly found a lack of financial support for access to follow-up and rehab services for cancer survivors in rural BC.<sup>7</sup> Further, studies have demonstrated increased difficulty of travelling for care among those with poor social supports.<sup>13,22</sup> This is particularly concerning for the elderly, who often rely on fixed incomes. Indeed, one study outlined multiple breaks in continuity of care experienced by seniors accessing care in the context of regionalization.<sup>23</sup> This is a pressing issue in Canada and other countries, where rural populations are ageing at a faster rate than urban populations.<sup>24</sup>

At the center of many of these obstacles in accessing care appears to be the lack of non-emergency transport. Some supports, including Health-Authority-operated bus services and reimbursement programs, do exist<sup>25</sup>; however, many participants desired more supports from the healthcare system to assist with travel. Similar to Howard *et al.*'s findings,<sup>7</sup> this study suggests that assisting rural patients with coordination of care could significantly improve their experiences with the medical system. This may in part be achieved through implementation of patient navigators, whose efficacy has been noted across multiple contexts.<sup>26-28</sup>

In our study, we found that participants required psychosocial or financial resources to overcome many of the challenges they faced in accessing care. Patients often had to be proactive in organizing their own care; this represents an additional 'cost' faced by rural residents in accessing care. Many of these challenges are specific to the rural context, and studies have shown that the determinants of satisfaction of medical care are unique for patients from rural communities.<sup>29</sup> Healthcare planning needs to consider the unique needs of rural patients and develop strategies to better support them. This is key to reducing inequities in access to care and health outcomes that exist between rural and urban populations. Some system adaptations for rural patients may even lead to a decrease in healthcare expenditures. A recent study exploring the costs of different modes of rural psychiatric



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