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An assessment of barriers to accessing health care for medical travellers from Canada’s far north: highlighting opportunities for improving patient experiences

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Title: An assessment of barriers to accessing health care for medical travellers from Canada's far north: highlighting opportunities for improving patient experiences

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ABSTRACT

Objectives: This paper explores patient experiences and identifies barriers and opportunities for improving access to healthcare for patients from the Canadian north who travel to receive medical care in a southern province.

Design: A mixed-methods, cross-sectional study involved one-on-one interviews, focus group discussions, and key informant interviews.

Participants: 52 one-on-one interviews with Northwest Territories (NWT) patients and patient escorts and two focus group discussions (n=10). Fourteen key informant interviews were conducted with health workers, program managers, and staff of community organizations providing services for out-of-province patients. A Community Advisory Board guided the development of the questionnaires and interpretation of results.

Results: Respondents were satisfied with the care received overall, but described unnecessary burdens and bureaucratic challenges throughout the travel process. Themes relating to access to healthcare included: plans and logistics for travel; level of communication between services; clarity around jurisdiction and responsibility for care; indirect costs of travel and direct costs of uninsured services; and having a patient escort or advocate available to assist with appointments and navigate the system. Three themes related to healthcare experiences included: cultural awareness; respect and caring; and medical translation. Respondents provided suggestions to improve access to care.

Conclusions: Patients from NWT need more information and support before and during travel. Ensuring that medical travelers and escorts are prepared before departing, that healthcare providers engage in culturally appropriate communication, and connecting travelers to support services upon arrival have the potential to improve medical travel experiences.

Keywords: Healthcare access, healthcare services, medical travel, northern Canada, patient experience

ARTICLE SUMMARY

Strengths and limitations of this study

- To our knowledge, this study is the first to explore the experience of out-of-territory travel from the perspective of patients, escorts, healthcare providers, and support staff in an urban centre.
- The mixed-methods design allowed the merging of data from different perspectives.
- More effective and transparent travel preparation and efficient communication across jurisdictions could improve the patient experience and reduce costs to the public healthcare system.
- The findings may not be generalizable to inpatients with potentially greater acute care needs, or to medical travel from other territories and to other provinces across Canada.

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- This study does not include individuals who were not able to get the required appointments, referrals, or the paperwork to travel. These circumstances amongst a potentially more vulnerable group of patients should not be overlooked.

BACKGROUND

In Canada's universal healthcare system, services are provided across a vast geography, in the context of decentralized management by provincial and territorial authorities, and based on principles of universality; comprehensiveness; portability; accessibility; and, public administration.[1] For residents of rural and remote areas of Canada, the majority of primary care services are met close to home in communities and regional centres. Remote communities in Canada's north are served through a nurse-based primary care model supported by periodic physician visits, and increasingly, telehealth services.[2] However, certain health conditions require travel to more specialized services that are only available in larger centres, sometimes outside the province or territory.

Out-of-province and out-of-territory medical travel in Canada comprises a small percentage of the total care provided, but it can be physically, financially, and emotionally challenging for patients, families, and communities, and it comes with a significant public sector cost.(1) The Government of Northwest Territories (NWT) provides medical travel benefits for NWT residents with a valid healthcare card, and administers the federally funded Non-Insured Health Benefits (NIHB) Program that covers registered First Nations and Inuit. NWT has the highest total health expenditure per capita in Canada.(2) NWT relies on four main territorial healthcare facilities, with specialized diagnostic and treatment services accessed outside the territory in Alberta, Saskatchewan, and British Columbia. Mainly, Alberta Health Services Edmonton Zone facilitates these placements through contractual arrangement. In 2016-2017, the NWT Department of Health and Social Services (DHSS) spent $32.5 million for residents to access medical services outside NWT, an increase compared to previous years, accounting for 7% of the total DHSS spending.(3)

The NWT DHSS released a revised medical travel policy in 2015 and accompanying guide in 2017.(4) The medical travel policy covers return airfare, inter-facility ambulance services for emergency medical evacuations, and some support for meals, accommodation, and ground transportation. Under certain circumstances, NWT covers for a non-medical escort to travel with and assist the patient.(4, 5)

Improving access to and experience with healthcare services has inherent value to health system users, and is associated with important clinical processes and outcomes,(6) especially in relation to chronic disease prevention and management,(7, 8) adherence to medical advice,(9) and treatment plans.(10)

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Recently, attention related to delivering better preventive and primary care close to home,(11) medical travel for pregnancy(12) and postnatal services,(13) and reducing the cost of medical travel(14) has increased, but with little focus on the experience of inter-province/territory medical travel.

This research identified barriers to accessing quality healthcare for medical travelers receiving care in another jurisdiction, and potential opportunities for improving care. We applied a mixed-methods research design, sequentially merging quantitative information from medical travelers and escorts from NWT, with qualitative analysis of travel experiences, and key informant interviews with frontline health workers, program managers, and staff of community organizations providing services for out-of-province patients.

METHODS

Setting

This study took place in Edmonton, the capital of the province of Alberta and closest major urban centre to NWT. Larga Edmonton is a boarding home providing accommodation, meals, and ground transportation to local medical appointments. Larga is a joint venture between Regional Development Corporations in NWT and Nunavut. Outpatient medical travelers and escorts stay at Larga, or, if visitor volume is high, in nearby hotels.

Study design

Through the mixed-methods design, we collected data in different ways.(15) Integrating qualitative and quantitative findings identified themes of access to and experiences with health services, and potential solutions. The qualitative key informant interviews were conducted August to September 2017 and informed the development of the questionnaire administered with medical travelers. Questionnaires were reviewed by the Community Advisory Board, and pilot tested before use. Focus group discussions with medical travelers and escorts provided additional context for the one-on-one interview data. Across all sources, more weight was placed on the open-ended narratives provided by participants. Interviews and focus group discussions were conducted November to December 2017.

Data collection

Two female interviewers (MO, KK) conducted all of the key informant interviews, focus group discussions, and the majority of the one-on-one interviews. At the time of the interviews, MO was a community

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organizer with significant lived experience as a northerner and KK was a PhD student with over 10 years of experience in quantitative and qualitative population research. Three female data collectors (SA, SL, SJ) conducted additional one-on-one interviews. The interviewers did not have an ongoing relationship with the participants.

Key informant interviews

Frontline health workers, program managers, and staff of community organizations providing services for out-of-province patients were purposively sampled, with a snowball sampling strategy until saturation was reached after fourteen interviews. Two female interviewers trained in study procedures conducted the interviews in private offices. Data collection consisted of face-to-face, semi-structured interviews 30-60 minutes in length. Interviews were audio recorded and later transcribed.

One-on-one interviews

Medical travelers and non-medical escorts residing at Larga were invited to participate. Individuals who were residents of NWT and had attended at least one medical appointment in Edmonton were eligible. The sample size was based on the number of medical travelers from NWT staying at Larga in a one-month period, accounting for an 80% response rate. In total 43 patients and 9 escorts participated. The interviewer-administered questionnaire consisted of socio-demographic characteristics, self-reported health status, and experiences with the health system and medical travel. The interviewer transcribed open-ended responses verbatim. Escorts were invited to participate if the patient was unavailable. Escorts responded to questions relating to travel and experience, but did not provide information related to specific health concerns of the patient. Interviews were conducted in private offices or unoccupied meeting rooms and took between 22-71 minutes to complete.

Focus group discussions

Ten patients and escorts explored issues in more detail in two semi-structured focus group discussions, advertised at Larga through word of mouth and posters. The discussions took place in the evening in a residence common area, and were approximately 60 minutes in length. One team member facilitated the discussion and one took field notes. Discussions were audio recorded and later transcribed.

Data analysis

Data were entered on a tablet using an online questionnaire developed with REDCap version 8.1.1.(16) Quantitative data were analyzed using Stata version 14.(17) KK and SA transcribed audio files. Transcripts were analysed using NVivo Pro version 12 to code and categorize the data using conventional content

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analysis.(18) In the analysis, access was defined as the ability of people to obtain appropriate healthcare resources to preserve or improve health.(19) Experience with health services and healthcare providers was defined as the range of interactions between individuals and the healthcare system, including care provided by doctors, nurses, and auxiliary staff.

Patient and public involvement

This study was part of a 4-year project on access to health services called Caring and Responding in Edmonton: The CARE Project. The inclusion of the experience of medical travelers came at the request of community partners and Government of the Northwest Territories. A 60+ member Community Advisory Board, including representatives from NWT and medical travel, helped guide the development of the questionnaires, interpretation, and dissemination of results. Results were presented to the CAB in May 2018, in a specific northern gathering in November 2018, and in NWT in January 2019. Engagement is ongoing with medical travelers and healthcare services providing services to out-of-province patients.

Ethics

University of Alberta's Human Research Ethics Board, and the Northern Alberta Clinical Trials and Research Centre granted ethical approval (PR00069624). Respondents were informed about the purpose of the study and provided written informed consent prior to participation.

RESULTS

Background characteristics and details of medical travel

Table 1 summarizes background characteristics of respondents. The shortest direct distance travelled to Edmonton was 725km, and the furthest was 2030km, with much greater actual travel distance. Figure 1 and Box 1 illustrate the medical travel journey.

Box 1. Example of a non-emergency medical travel journey

In remote northern communities, the development and preservation of local skills and knowledge provide strength and resiliency. Connecting with land, culture, and traditions is an important component of health and wellness in NWT, and beyond. However, when more complex health needs arise, residents may have to leave home for care.

There is no 'typical' medical travel journey. For most medical travel, residents need to see the visiting physician first, and some communities only have access to a doctor for three or four days every five weeks, resulting in potentially lengthy wait times. When a doctor refers a patient for travel, the patient is sent to

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the nearest regional centre, such as Inuvik or Yellowknife. Flight schedules vary, and most communities are not serviced by daily flights.

Weather delays are common all year round, so a single short appointment could result in a week away from home. Following the regional travel, and depending on the severity of the health concern and the treatment needed, the patient may end up being referred to Edmonton.

The cost of accommodation, food, most medical, and travel costs are covered by the Government of NWT or the federal government, and supplementary health insurance programs. However, medical travelers can be out of pocket for incidental costs, and may have to pay up front for prescription drugs.

Under certain circumstances, a non-medical escort may accompany the patient, but frequently, adult patients travel alone. Regular frustrations of travel such as flight delays or scheduling changes, lost luggage, unfamiliar signage, and adjusting to new accommodation, can become overwhelming during medical travel. The steps depicted are not uncommon, with one individual needing to travel over 5,000km for a single health concern, resulting in weeks away from home.

People from the most remote communities experienced increased burdens, and mobility or illness made the journey more challenging.

> *Some people are on oxygen or in a wheelchair.…You spent two days traveling and you are here for a half hour appointment. Then sometimes…it could take them a few days to get home because of weather. And then it's supposed to be one night in Yellowknife and it ends up being five or six. (key informant, 603)*

The average stay at Larga was 9 days, and 77% of respondents were first-time Larga residents. 19% had been staying for over two weeks, with 75 days being the longest stay. The majority of respondents were satisfied with the care they received in Edmonton (Figure 2).

The single biggest challenge reported was making arrangements for children, pets, and other household responsibilities while away (Figure 3). This was particularly true for patients without definitive return dates. One respondent described: "The last time we were here, we didn't know that we'd be here for two months" (medical traveler, 3522).

Respondents described the impact of delays between obtaining approval and receiving care: "By the time [the patient] found out that he had cancer, it had metastasized already. Medical information took forever to reach us" (patient escort, 3524). The perceived consequences of not being proactive were severe: "You really have to be up on your care. As some of my friends who did not push, now they are dead" (medical traveler, 3527).

Factors influencing access to care

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Five main themes were derived from the data (Table 2): 1) medical travel logistics; 2) level of communication between services; 3) clarity around jurisdiction and responsibility for care; 4) cost of services, and 5) having an escort or advocate.

Medical travel logistics

Of respondents who reported difficulties, 5.0% identified that travel to an unfamiliar city was the single most challenging. The city's size and range of services was described as overwhelming, especially in comparison to northern communities. The ability to navigate complicated logistics had an impact on access to care. Respondents noticed limited information provided before travel, and unclear process of determining itineraries. As one traveler explained, "[Before travel we need] more information, more understanding. Give information to patients in plain, understandable words" (medical traveler, 5502).

Communication between services

Limited communication between various levels of care and from decision makers could impact care. Respondents noted that healthcare providers in Edmonton are not always aware of the care that is available in the patients' home communities. Continuity of care is a challenge given that small, remote and isolated communities often have locum doctors, and a high turnover amongst providers.

Jurisdiction and responsibility for care

Reciprocal billing and aligning policies and procedures in the different health jurisdictions were described as recurrent obstacles. Medical travelers and non-clinical program staff were unclear about what services were covered, and what to do when patients were turned away. Refusing or delaying services to patients that did not have an Alberta health insurance number was reported. The process of getting proof of NIHB Program benefits was frequently noted as a challenge.

Direct and indirect costs

While some respondents appreciated the range of costs associated with medical travel that were covered, and around two-thirds of respondents had access to supplemental health coverage, 23% identified access to funds as a barrier in accessing needed care, and one third of them cited lack of coverage for medications as the main gap.

Non-medical escorts and facilitated appointments

Having a companion to attend appointments and act as a support and advocate, particularly someone who is familiar with the patient's home community and Edmonton was reported to increase access and

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positive care experiences. While navigator services exist at larger facilities, few local programs are specific to northern Indigenous cultures, and not all respondents were aware of these services.

Factors influencing the experience of care

Three themes affecting experience with healthcare providers and related solutions emerged from the data (Table 2): 1) cultural awareness; 2) respect and caring; and, 3) medical translation.

Cultural safety and awareness

Respondents described the benefit of welcoming and safe environments that provide high quality, trauma-informed and culturally appropriate care. Healthcare providers and staff that exhibited cultural competence were greater support to patients. Respondents expressed concern about experiencing discrimination. To increase empathy related to medical travel, one respondent suggested: "taking health providers through what it must be like to come to a new place, [with] traffic lights, and people, and noise, and trees" (key informant, 605).

Respect and caring

Especially for people traveling alone, or facing traumatic circumstances, providers could offer extra respect and caring for patients who are far from home. One respondent recounted the story of a young woman who had an emergency evacuation from a small community during a high-risk pregnancy. She traveled with nothing and could not get a bag of her own things sent down, thus she relied on donations of toiletries and clothing.

Medical translation

Communicating medical information with providers was mentioned as a challenge for numerous respondents, especially for the 17% whose primary language was not English. Respondents described some benefits and drawbacks of professional translator services compared to having an escort in the appointment.

INTERPRETATION

In this study, medical travelers, escorts, and support workers, were interviewed in the context of a larger project on improving access to healthcare for vulnerable populations. Medical travelers from NWT are a unique and vulnerable population that could benefit from increased access to and continuity of care.

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Effective and transparent travel preparation, efficient communication across jurisdictions, and addressing systemic and individual-level discrimination were key areas for improvement.

Many medical travelers appreciated the care received in Edmonton, while also reporting the stress involved with managing travel logistics across different health jurisdictions. With no direct flights to Edmonton from most communities, the first leg involves traveling to the nearest larger centre in NWT, which can add a day or more to the trip, with no designated facility or support for infirm travelers. This 'multi-locality' of individuals moving between home, regional centres, and Edmonton, can become a long-term feature of peoples' lives,(20) creating disruptions to personal, family, community and cultural obligations.(12)

Many NWT residents travel to access advanced medical care at some point.(21) Such travel is further complicated by complex policies affecting healthcare delivery for Indigenous peoples.(21) Detailed policies surrounding medical travel and NIHB assure standardization, but are not applied uniformly. This may reduce the ability to respond to shifting patient needs in dynamic situations, such as long-distance travel during a period of illness or injury.(20) Electronic health records between NWT and Alberta have allowed for more efficient sharing of patient information, but barriers to full utilization of the system exist and important medical information does not always travel with patients to other jurisdictions.(22, 23) Medical travelers paid out-of-pocket for incidentals and some prescriptions and procedures, and some could not access social assistance benefits or bank accounts away from home. Inter-jurisdiction coordination has been a long-standing challenge, with negative consequences for health outcomes.(20)

Patient escorts were described as an important source of support and advocacy. Family members can support decision-making and adherence to treatment plans,(21) but aren't always the best escorts.(24) Even with changes to the patient escort policy,(20, 24) respondents echoed that challenges still exist, such as unreliable escorts, and inconsistent policy application. For patients alone, a local trained navigator or advocate could help with medical communication, providing emotional and cultural support.(25) Communication pre-departure and during the course of travel and treatment should utilize different formats and media to reach a larger audience with targeted information.

Participants called for more culturally appropriate care and communication. Medical travel can create additional challenges for an already vulnerable person in a health crisis. Access to information and communication were particular areas of concern. Communication was often complicated by language and culture, and challenges with health communication and health literacy may prove particularly harmful.(21, 26, 27) Respondents described the care and support provided by an Indigenous clinic, cultural helpers,

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and a local northern support unit, as extremely valuable. However, not all travelers were aware of or able to connect to services and resources.

In our study, 15-18% of respondents did not feel listened to or respected, and felt discriminated against during most recent care experiences. Respondents described the impact of negative healthcare experiences on health-seeking behaviours in general. The unequal patient-provider power dynamic in health care, particularly within a colonialist historical context, is well described.(28-30) Relying on patients to advocate for their health and needed services, underestimates the complex power relationships involved. Eight of the 94 summary recommendations arising from Canada's Truth and Reconciliation Commission specifically pertain to health.(31) Greater understanding of how residential schools, forced relocation and systemic discrimination have shaped Canada's northern communities, and how to use that knowledge to change healthcare service delivery is still needed.

The barriers to medical travel can be overwhelming, leading to delays in receiving care, or an avoidance of care-seeking altogether,(32) resulting in poorer outcomes and higher costs for aggravated health conditions.(33) Continuity of care remains a challenge in the North; with only 31.1% of Indigenous territorial residents seeing a regular doctor, compared to 76.4% of Indigenous people outside the territories.(34) One systematic review of the impact of distance to healthcare services on health outcomes in northern settings found worse health outcomes amongst patients living further away from healthcare facilities and concluded that distance should be a consideration in discussions of treatment options.(32)

To our knowledge, this study is the first to explore the experience of out-of-territory travel from the perspective of outpatients, escorts, providers and support staff in an urban centre. The mixed-methods design allowed the merging of data from different perspectives. One limitation is the subjective measuring of patient perceptions of experience and access. Moreover, the findings may not be generalizable to inpatients with potentially greater acute care needs, or to medical travel from other territories and to other provinces across Canada. Finally, because the interviews were conducted at the point of care, they were not with individuals who were not able to get the required appointments, referrals, or the paperwork to travel. These circumstances amongst a potentially more vulnerable group of patients should not be overlooked.

The majority of medical travelers from NWT were satisfied with the care in Edmonton. However, many also encountered serious challenges with medical travel, including significant delays in accessing and receiving care. Patients outside of their home jurisdiction are a unique and potentially vulnerable population that could benefit from increased access to and continuity of care. Healthcare providers and

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policy makers may not be aware of the complexity of the medical travel experience and the stress involved with managing travel logistics across different health jurisdictions. More effective and transparent travel preparation and efficient communication across jurisdictions and with patients could help improve the experience of medical travel for residents of the far north.

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Author contributions: SS, FK, KK conceptualized the study, analyzed, and interpreted the data. KK wrote the first draft and all authors contributed to revisions. MO, SL, SJ, SA collected data, and supported analysis and interpretation. MO, MQ SIF, CM, SB, DD, AC contributed to interpretation of results, writing and review of the manuscript. All authors approved the final manuscript. Each author has reviewed and approved the contents of the submitted manuscript for publication.

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Table 1. Self-reported characteristics of Larga clients interviewed, n=52

	N	%
Age group (years)		
18-24	2	3.8%
25-44	11	21.2%
45-64	27	51.9%
65+	12	23.1%
Gender		
Male	29	55.8%
Female	23	44.2%
Ethnicity		
First Nations	20	38.5%
Inuit	10	19.2%
Métis	4	7.7%
Non-Indigenous	18	34.6%
Education (highest level attained)		
Less than high school diploma	19	36.5%
High school diploma	10	19.2%
Some post-secondary	5	9.6%
Post-secondary degree or diploma	18	34.6%

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Table 2. Themes arising from interviews with key informants, medical travelers, patient escorts, and focus group discussions

	Opportunities to improve access and experience	**Participant quotes**	**Proposed solutions**
Access to services	(1) Improve information and logistics prior to travel	It's like traveling to a foreign country, like hearing that you're going to go to India tomorrow. You wouldn't even be worried about the procedure; you'd be worried whether all of the things that you've heard are true. What will I eat? Do I have the right clothes? And the airport security? That even makes me nervous. (key informant, 305)	• Increase awareness and distribution of the NWT medical travel guide • Provide information to travelers and medical travel staff on various medical travel scenarios, and what to expect on arrival • Develop user-friendly communication methods and materials regarding itinerary and flight options
		You come inside at the [University of Alberta Hospital] and there's a big rush. You need to ask someone where reception is…. Some of the reception areas [in the hospital] are bigger than most health centres in the communities. And that's intimidating, especially to older people, Elders. An Elder doesn't want to get lost. (focus group, 352)	
	(2) Increase effective communication between services	The people who are in charge of the medical travel have the power to decide if you are going or not for medical….If the medical travel staff say no, then you don't get sent out…I was told by the Doctor that I needed to go for MRI and I ended up not going and it was never explained why I didn't end up going. (focus group, 351)	• Enhance connections between health professionals, administrators and community organizations providing care and support to medical travelers to raise awareness about the various services available • Spread awareness amongst local service providers about medical travel and the services available both in Edmonton and in NWT
		[My community's] problem is the doctors kept changing month to month. It was confusing patients. One would send for this test; one would send for that test. There was no steady [person]. So when the doctors [in Edmonton] ask, "you got a physician back at home?" you laugh. (focus group, 352)	
	(3) Reduce jurisdictional and bureaucratic barriers	Homecare is not reciprocally billed, and palliative care is not an insured service, and long-term care access is not assured by the contracts that we currently have. … [If a patient from the North is] down here and needs long-term care access, our only resource is to repatriate them to the nearest hospital, and they start the process from the North. This becomes a problem…but we do try to cobble together some things. –(key informant, 120)	• Clarify protocol for out-of-province patients with frontline staff and healthcare providers • Ensure jurisdictional issues do not become barriers to patient care

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Opportunities to improve access and experience		**Participant quotes**	**Proposed solutions**
		…[S]ome of the healthcare professionals get very disgruntled with you if you don't have an Alberta [Personal Health Card]…[We hear,] "No you can't get in to see this particular person because you don't have Alberta healthcare." (key informant, 607)	
	(4) Reduce the financial burden	While back home all the medication was paid for, here we have to wait for reimbursement. I don't understand that some medications you have to pay [for] and not some others. (medical traveler, 3505)	• Ensure that medical travelers are aware of coverage restrictions and policies and have access to funds locally • Communicate potential for out-of-pocket costs associated with care and medications, and provide financial support options for medical travel.
		Sometimes [patients] need to do prep work for appointments, and then they get here and they have to buy this stuff, and have no money, and it's not covered. But if they don't get the prep work they don't get the procedure. (key informant, 305)	
	(5) Provide opportunities for facilitated appointments	The information form I was given [at my consultation] said, "please consider having someone with you post-op." I felt like that wasn't fair because I didn't get to consider that. Medical travel wouldn't allow [an escort]. (medical traveler, 1501)	• Clear communication and adherence to the medical escort policy • Expand the number and scope of patient navigators who can facilitate continuity of care and support throughout a patient's stay in Edmonton, from arrival, to hospital and/or clinics, and back. • Document and disseminate best practices of healthcare navigators
		With the traveling, I would like to see them change the policy with escorts and long term [travel]….I have to travel all by myself because my escort would have to pay her own travel fees. They should allow an escort to come with you regardless if [the escort is] only staying for a week but you are staying for 4 weeks. I have to fly home by myself and it's not easy. (medical traveler, 2501)	
Experience with providers	(1) Increase cultural awareness	There is blatant discrimination and racism all the time. And I don't think people talk about that enough. As a society we push it under the carpet and we don't realize how traumatizing that is to a person. People just don't know about Aboriginal culture and people are not looked at as being on the same level as other people in the country…once you've been on the receiving end of that discrimination you just kind of give up. (key informant, 305)	• Promote the uptake of cultural awareness and cultural safety classes for healthcare providers, frontline staff, and auxiliary staff • Increase the northern-specific content included in cultural training for

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Opportunities to improve access and experience	Participant quotes	Proposed solutions
	[My care would be improved by] doctors understanding where I am coming from: a small town, a long distance, culturally. (medical traveler, 8506)	healthcare providers and frontline staff to provide more information on the specific challenges of northern patients • Provide outreach opportunities to promote hands-on experiences and cultural learning directly with community members
(2) Facilitate respectful and patient-centred care	I understand it gets busy and stuff like that but we're still human. Each person should still be treated respectfully in any manner. (key informant, 142)	
	Not everybody thinks the same, believes the same or practices the same. So it's having that respect and starting out from a blank page and saying, "let's get to know you." …That's part of the relationship.(key informant, 302)	
(3) Expand access to medical translation and understanding	[The language service does not] have Slavey or Tłı̨chǫ or Inuinnaqtun, Gwich'in. …But how often do we need a Slavey translator? Most people who come who need a translator are Elders anyway and so they would be coming with an escort. The [GNWT] tries to ensure that the escort is comfortable doing this. Sometimes they get someone who is really not suitable. Like you get a 16-year-old coming down with their grandfather with cancer of the rectum. (key informant, 120)	• Ensure that health providers know how to access translation services, including which languages are available through telephone translation • Engage local trained navigators or advocates to support medical communication • Provide travel information as well as health information materials for medical travelers in northern Indigenous languages
	The language barrier, not so much for me, but other people from Délı̨ne, there's no one who speaks the language. Even the people escorting, their education level isn't that high. So now you have two people lost, trying to find their way to an appointment. My wife's aunt got lost here for a day and a half. She went to an appointment but never made it because she couldn't find it…There's a language barrier especially for the old ones. The Elders have the hardest time of all. (focus group, 352)	

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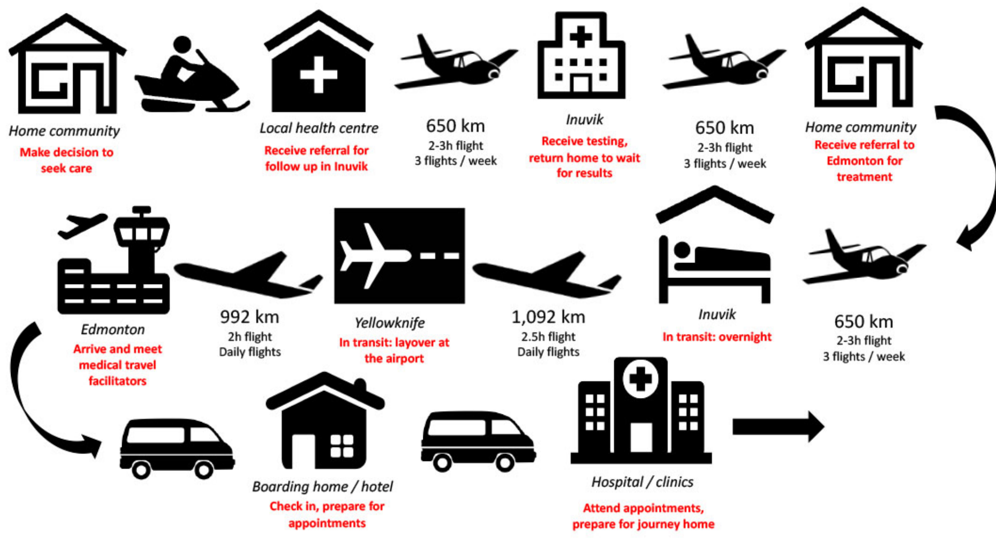

Example of a non-emergency medical travel journey

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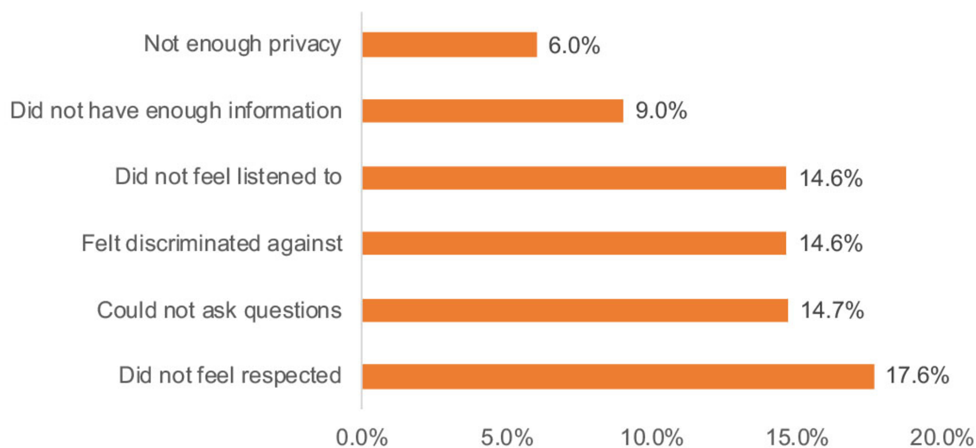

Satisfaction with most recent healthcare experience in Edmonton (n=34)

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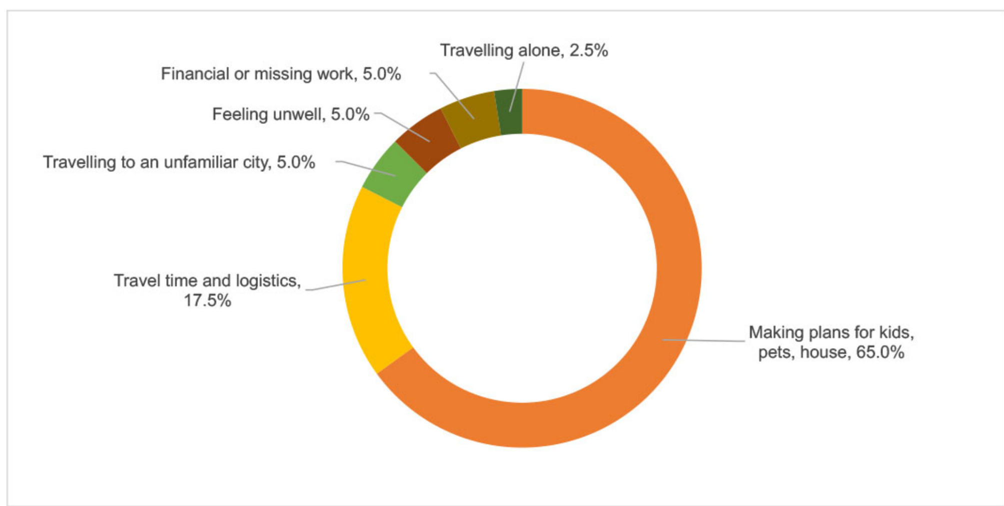

The main difficulty related to medical travel (amongst those who reported, n=40)

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Consolidated criteria for reporting **qualitative studies** (COREQ): 32-item checklist

No	Item	Guide questions/description	Page, line
Domain 1: Research team and reflexivity			
Personal Characteristics			
1.	Interviewer/ facilitator	Which author/s conducted the interview or focus group?	Page 4, line 29-37
2.	Credentials	What were the researcher's credentials? *E.g. PhD, MD*	Page 4, line 29-37
3.	Occupation	What was their occupation at the time of the study?	Page 4, line 29-37
4.	Gender	Was the researcher male or female?	Page 4, line 29, 34
5.	Experience and training	What experience or training did the researcher have?	Page 4, line 27-35
Relationship with participants			
6.	Relationship established	Was a relationship established prior to study commencement?	Page 4, line 36-37
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. *personal goals, reasons for doing the research*	Page 5, line 41-46
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. *Bias, assumptions, reasons and interests in the research topic*	Page 4, line 27-35
Domain 2: study design			
Theoretical framework			
9.	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? *e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis*	Page 5, line 29-37
Participant selection			
10.	Sampling	How were participants selected? *e.g. purposive, convenience, consecutive, snowball*	Page 4, line 40-43; 51-53; page 5, line 16-18
11.	Method of approach	How were participants approached? e.g. *face-to-face, telephone, mail, email*	Page 4, line 40-43; 51-53; page 5, line 16-18
12.	Sample size	How many participants were in the study?	Page 4, line 45; page 5, line 10, 16

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13.	Non-participation	How many people refused to participate or dropped out? Reasons?	Not captured
Setting			
14.	Setting of data collection	Where was the data collected? e.g. *home, clinic, workplace*	Page 4, line 47; 53; page 5, line 16, 20
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?	No.
16.	Description of sample	What are the important characteristics of the sample? *e.g. demographic data, date*	Table 1
Data collection			
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Page 4, line 20
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?	No.
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?	Page 4, line 48; Page 5, line 23
20.	Field notes	Were field notes made during and/or after the interview or focus group?	During; page 5, line 23
21.	Duration	What was the duration of the interviews or focus group?	Page 4, line 47; Page 5, line 13, 21,
22.	Data saturation	Was data saturation discussed?	Page 4, line 45
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	No
Domain 3: analysis and findings			
Data analysis			
24.	Number of data coders	How many data coders coded the data?	Page 5, line 30
25.	Description of the coding tree	Did authors provide a description of the coding tree?	No.
26.	Derivation of themes	Were themes identified in advance or derived from the data?	Page 6, line 42; Page 7, line 49
27.	Software	What software, if applicable, was used to manage the data?	Page 5, line 30
28.	Participant checking	Did participants provide feedback on the findings?	No.
Reporting			
29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. *participant number*	Table 2
30.	Data and findings consistent	Was there consistency between the data presented and the findings?	Table 2

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31.	Clarity of major themes	Were major themes clearly presented in the findings?	Table 2
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Table 2

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STROBE Statement—Checklist of items that should be included in reports of ***cohort studies***

	Item No	Recommendation	Page, Line
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	Title
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	Abstract
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	Page 3; Line 5-40
Objectives	3	State specific objectives, including any pre-specified hypotheses	Page 3; Line 42-49
Methods			
Study design	4	Present key elements of study design early in the paper	Page 4; Line 13-24
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	Page 4; Line 3-36
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up	Page 4; 51-57
		(*b*) For matched studies, give matching criteria and number of exposed and unexposed	N/A
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	Page 5; 3-13
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	Page 4; 51-57, Page 5, 3-13
Bias	9	Describe any efforts to address potential sources of bias	Page 10; 20-29
Study size	10	Explain how the study size was arrived at	Page 4; 55-57
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	Page 5; 3-13

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Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	N/A
		(*b*) Describe any methods used to examine subgroups and interactions	Table 1
		(*c*) Explain how missing data were addressed	Page 5; 3-13
		(*d*) If applicable, explain how loss to follow-up was addressed	N/A
		(*e*) Describe any sensitivity analyses	N/A
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	Reported on each table / figure
		(b) Give reasons for non-participation at each stage	Page 5; 3-13
		(c) Consider use of a flow diagram	N/A
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	Table 1
		(b) Indicate number of participants with missing data for each variable of interest	Reported on each table / figure
		(c) Summarise follow-up time (eg, average and total amount)	N/A
Outcome data	15*	Report numbers of outcome events or summary measures over time	N/A
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	N/A
		(*b*) Report category boundaries when continuous variables were categorized	Table 1
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	N/A
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	N/A

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BMJ Open

Opportunities for improving patient experiences among medical travelers from Canada's far north: a mixed methods study

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Title: Opportunities for improving patient experiences among medical travelers from Canada's far north: a mixed methods study

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ABSTRACT

Objectives: This paper explores patient experiences and identifies barriers and opportunities for improving access to healthcare for patients from the Canadian north who travel to receive medical care in a southern province.

Design: A mixed-methods, cross-sectional study involved one-on-one interviews, focus group discussions, and key informant interviews.

Participants: 52 one-on-one interviews with Northwest Territories (NWT) patients and patient escorts and two focus group discussions (n=10). Fourteen key informant interviews were conducted with health workers, program managers, and staff of community organizations providing services for out-of-province patients. A Community Advisory Board guided the development of the questionnaires and interpretation of results.

Results: Respondents were satisfied with the care received overall, but described unnecessary burdens and bureaucratic challenges throughout the travel process. Themes relating to access to healthcare included: plans and logistics for travel; level of communication between services; clarity around jurisdiction and responsibility for care; indirect costs of travel and direct costs of uninsured services; and having a patient escort or advocate available to assist with appointments and navigate the system. Three themes related to healthcare experiences included: cultural awareness; respect and caring; and medical translation. Respondents provided suggestions to improve access to care.

Conclusions: Patients from NWT need more information and support before and during travel. Ensuring that medical travelers and escorts are prepared before departing, that healthcare providers engage in culturally appropriate communication, and connecting travelers to support services upon arrival have the potential to improve medical travel experiences.

Keywords: Healthcare access, healthcare services, medical travel, northern Canada, patient experience

ARTICLE SUMMARY

Strengths and limitations of this study

- To our knowledge, this study is the first to explore the experience of medical travel in Canada from the perspective of patients, escorts, healthcare providers, and support staff in an urban centre.
- The mixed-methods design allowed the merging of data from different perspectives and findings will be of interest to other healthcare jurisdictions serving large remote and isolated populations.
- This study was able to document culturally-relevant and patient-centred solutions to improve travel preparation and communication that would have a positive impact on patient experience and reduce healthcare costs.
- The majority of respondents reported receiving outpatient, schedulable services, and findings may not be generalizable to inpatients with acute or emergency care needs.

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- Further research is required to implement and test patient-led solutions, and to identify and address pre-travel barriers to healthcare access.

BACKGROUND

In Canada's universal healthcare system, services are provided across a vast geography, in the context of decentralized management by provincial and territorial authorities, and based on principles of universality; comprehensiveness; portability; accessibility; and, public administration.(1) For residents of rural and remote areas of Canada, the majority of primary care services are met close to home in communities and regional centres. Remote communities in Canada's north are served through a nurse-based primary care model supported by periodic physician visits, and increasingly, telehealth services. However, certain health conditions require travel to more specialized services that are only available in larger centres, sometimes outside the province or territory. Only 3% of specialists live in rural or remote areas of Canada, where over 18% of the population resides.(2)

Out-of-province and out-of-territory medical travel in Canada comprises a small percentage of the total care provided, but it can be physically, financially, and emotionally challenging for patients, families, and communities, and it comes with a significant public sector cost.(3) The Government of Northwest Territories (NWT) provides medical travel benefits for NWT residents with a valid healthcare card, and administers the federally funded Non-Insured Health Benefits (NIHB) Program that covers registered First Nations and Inuit. NWT has the highest total health expenditure per capita in Canada.(4) NWT relies on four main territorial healthcare facilities, with specialized diagnostic and treatment services accessed outside the territory in Alberta, Saskatchewan, and British Columbia. In 2016-2017, the NWT Department of Health and Social Services (DHSS) spent $32.5 million for residents to access medical services outside NWT, an increase compared to previous years, accounting for 7% of the total DHSS spending.(5)

The NWT DHSS released a revised medical travel policy in 2015 and accompanying guide in 2017.(6) The medical travel policy covers return airfare, inter-facility ambulance services for emergency medical evacuations, and some support for meals, accommodation, and ground transportation. Under certain circumstances, NWT covers for a non-medical escort to travel with and assist the patient.(6, 7)

Improving access to and experience with healthcare services has inherent value to health system users, and is associated with important clinical processes and outcomes,(8) especially in relation to chronic disease prevention and management,(9, 10) adherence to medical advice,(11) and treatment plans.(12) Recently, attention related to delivering better preventive and primary care close to home,(13) medical

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travel for pregnancy(14) and postnatal services,(15) and reducing the cost of medical travel(16) has increased, but with little focus on the experience of inter-province/territory medical travel.

This research aimed to identify barriers to accessing quality healthcare for medical travelers and potential opportunities for improving care. We applied a mixed-methods research design, sequentially merging quantitative information from medical travelers and escorts from NWT, with qualitative analysis of travel experiences, and key informant interviews with frontline health workers, program managers, and staff of community organizations providing services for out-of-province patients.

METHODS

Setting

This study took place in Edmonton, a provincial capital and closest major urban centre to NWT, with a population of 1 million people. Medical travelers are provided accommodation in a boarding facility and transportation to local medical appointments. If patient volume is high, accommodation is provided at local motels.

Study design

Through the mixed-methods design, we collected data in different ways.(17) Integrating qualitative and quantitative findings identified themes of access to and experiences with health services, and potential solutions. The qualitative key informant interviews were conducted August to September 2017 and informed the development of the questionnaire administered with medical travelers. Questionnaires were reviewed by the Community Advisory Board, and pilot tested before use. Focus group discussions with medical travelers and escorts provided additional context for the one-on-one interview data. Across all sources, more weight was placed on the open-ended narratives provided by participants. Interviews and focus group discussions were conducted November to December 2017.

Data collection

Two interviewers (MO, KK) conducted all of the key informant interviews, focus group discussions, and the majority of the one-on-one interviews. MO is a community organizer with lived experience as an Indigenous woman and northerner. KK is a female PhD student with over 10 years of experience in cross-cultural quantitative and qualitative population research. Three female data collectors (SA, SL, SJ) conducted additional one-on-one interviews. The interviewers did not have an ongoing relationship with

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the participants, but all members of the data collection team spent significant time with staff and residents at the boarding facility building trust, sharing daytime and evening meals, playing games, crafting, and sharing information about the potential outcomes of the project.

Key informant interviews

Frontline health workers, program managers, and staff of community organizations providing services for out-of-province patients were purposively sampled, with a snowball sampling strategy until saturation was reached after fourteen interviews. Two female interviewers trained in study procedures conducted the interviews in private offices. Data collection consisted of face-to-face, semi-structured interviews 30-60 minutes in length. Interviews were audio recorded and later transcribed.

One-on-one interviews

Medical travelers and non-medical escorts residing at the boarding facility were invited to participate. Individuals who were residents of NWT and had attended at least one medical appointment in Edmonton were eligible. The sample size was based on the number of medical travelers from NWT in a one-month period, accounting for an 80% response rate. In total 43 patients and 9 escorts participated. The interviewer-administered questionnaire consisted of socio-demographic characteristics, self-reported health status, and experiences with the health system and medical travel. The interviewer transcribed open-ended responses verbatim. Patient escorts were invited to participate if the patient was unavailable. Escorts responded to questions relating to travel and experience, but did not provide information related to specific health concerns of the patient. Interviews were conducted in private offices or unoccupied meeting rooms and took between 22-71 minutes to complete.

Focus group discussions

Ten patients and escorts explored issues in more detail in two semi-structured focus group discussions, advertised locally through word of mouth and posters. The discussions took place in the evening in a residence common area, and were approximately 60 minutes in length. One team member facilitated the discussion and one took field notes. Discussions were audio recorded and later transcribed.

Data analysis

Data were entered on a tablet using an online questionnaire developed with REDCap version 8.1.1.(18) Quantitative data were analyzed using Stata version 14.(19) KK and SA transcribed audio files. Transcripts were analysed using NVivo Pro version 12 to code and categorize the data using conventional content analysis.(20) In the analysis, access was defined as the ability of people to obtain appropriate healthcare

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resources to preserve or improve health.(21) Experience with health services and healthcare providers was defined as the range of interactions between individuals and the healthcare system, including care provided by doctors, nurses, and auxiliary staff.

Patient and public involvement

This research was part of a 4-year mixed-methods implementation research study on access to health services called Caring and Responding in Edmonton: The CARE Project. The inclusion of the experience of medical travelers came at the request of community partners and Government of the Northwest Territories. A 60+ member Community Advisory Board, including representatives from NWT and medical travel, helped guide the development of the questionnaires, interpretation, and dissemination of results. Results were presented to the Community Advisory Board in May 2018, in a specific northern gathering in November 2018, and in NWT in January 2019. Engagement is ongoing with medical travelers and healthcare providers to improve patient navigation, communication, and experience through the intervention phase of The CARE Project.

Ethics

University of Alberta's Human Research Ethics Board, and the Northern Alberta Clinical Trials and Research Centre granted ethical approval (PR00069624). Respondents were informed about the purpose of the study and provided written informed consent prior to participation.

RESULTS

Background characteristics and details of medical travel

Table 1 summarizes background characteristics of respondents. The shortest direct distance travelled to Edmonton was 725km, and the furthest was 2030km as the crow flies, with much greater actual travel distance. Figure 1 and Box 1 illustrate the medical travel journey.

Box 1. Example of a non-emergency medical travel journey

In remote northern communities, the development and preservation of local skills and knowledge provide strength and resiliency. Connecting with land, culture, and traditions is an important component of health and wellness in NWT, and beyond. However, when more complex health needs arise, residents may have to leave home for care.

There is no 'typical' medical travel journey. For most medical travel, residents will need to see the visiting healthcare provider first, and some communities only have access to a doctor for three or four days every five weeks, resulting in potentially lengthy wait times. When a doctor refers a patient for travel, the

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patient is sent to the nearest regional centre, such as Inuvik or Yellowknife. Flight schedules vary, and most communities are not serviced by daily flights.

The logistics of Arctic air travel are complex and conditions can include blowing snow, extreme wind, and whiteout. Special equipment and training is required for aircraft and crew and for patient care, and there is a significant risk of weather delays all year round. This means that a single short appointment could result in a week away from home. Following regional travel, and depending on the severity of the health concern and the treatment needed, the patient may end up being referred to a facility located thousands of kilometers south.

The cost of accommodation, food, most medical, and travel costs are covered by the Government of NWT or the federal government, and supplementary health insurance programs. However, medical travelers can be out of pocket for incidental costs, and may have to pay up front for prescription drugs.

A non-medical escort may accompany the patient, but frequently, adult patients travel alone. Regular frustrations of travel such as flight delays or scheduling changes, lost luggage, unfamiliar signage, and adjusting to new accommodation, can become overwhelming during medical travel. The steps depicted are not uncommon, with one individual needing to travel over 5,000km for a single health concern, resulting in weeks away from home.

People from the most remote communities experienced increased burdens, and mobility or illness made the journey more challenging.

> *Some people are on oxygen or in a wheelchair....You spent two days traveling and you are here for a half hour appointment. Then sometimes…it could take them a few days to get home because of weather. And then it's supposed to be one night in Yellowknife and it ends up being five or six.* (key informant, 603)

The average stay in Edmonton was 9 days, and 77% of respondents were first-time visitors to the boarding facility. 19% had been staying for over two weeks, with 75 days being the longest stay. The majority of respondents were satisfied with the care received (Figure 2). The single biggest challenge reported was making arrangements for children, pets, and other household responsibilities while away (Figure 3). This was particularly true for patients without definitive return dates. One respondent described: "The last time we were here, we didn't know that we'd be here for two months" (medical traveler, 3522).

Respondents described the impact of delays between obtaining approval and receiving care: "By the time [the patient] found out that he had cancer, it had metastasized already. Medical information took forever to reach us" (patient escort, 3524). The perceived consequences of not being proactive were severe: "You really have to be up on your care. As some of my friends who did not push, now they are dead" (medical traveler, 3527).

Factors influencing access to care

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Five main themes were derived from the data (Table 2): 1) medical travel logistics; 2) level of communication between services; 3) clarity around jurisdiction and responsibility for care; 4) cost of services, and 5) having an escort or advocate.

Medical travel logistics

Of respondents who reported difficulties, 5.0% identified that travel to an unfamiliar city was the single most challenging. The city's size and range of services was described as overwhelming, especially in comparison to northern communities. The ability to navigate complicated logistics had an impact on access to care. Respondents noticed limited information provided before travel, and unclear process of determining itineraries. As one traveler explained, "[Before travel we need] more information, more understanding. Give information to patients in plain, understandable words" (medical traveler, 5502).

Communication between services

Limited communication between various levels of care and from decision makers could impact care. Respondents noted that healthcare providers in Edmonton are not always aware of the care that is available in the patients' home communities. Continuity of care is a challenge given that remote and isolated communities rely on visiting healthcare providers from southern centres, and there is a high turnover amongst providers.

Jurisdiction and responsibility for care

Reciprocal billing and aligning policies and procedures in the different health jurisdictions were described as recurrent obstacles. Medical travelers and non-clinical program staff were unclear about what services were covered, and what to do when patients were turned away. Refusing or delaying services to patients that did not have an Alberta health insurance number was reported by travelers and patient escorts. The process of getting proof of NIHB Program benefits was frequently noted as a challenge.

Direct and indirect costs

While some respondents appreciated the range of costs associated with medical travel that were covered, and around two-thirds of respondents had access to supplemental health coverage, 23% identified access to funds as a barrier in accessing needed care, and one third of them cited lack of coverage for medications as the main gap.

Non-medical escorts and facilitated appointments

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Having a companion to attend appointments and act as a support and advocate, particularly someone who is familiar with the patient's home community and Edmonton was reported to increase access and positive care experiences. While navigator services exist at larger facilities, few local programs are specific to northern Indigenous cultures, and not all respondents were aware of these services.

Factors influencing the experience of care

Three themes affecting experience with healthcare providers and related solutions emerged from the data (Table 2): 1) cultural safety and awareness; 2) respect and caring; and, 3) medical translation.

Cultural safety and awareness

Respondents described the benefit of welcoming and safe healthcare environments that provide high quality, trauma-informed, and culturally appropriate care. Healthcare providers and staff that exhibited cultural competence were described as providing better support to patients. Respondents shared past experiences of discrimination towards Indigenous patients and expressed concern about a lack of understanding in the healthcare system about the cultural and historical context of different communities. To increase empathy related to medical travel, one respondent suggested: "taking health providers through what it must be like to come to a new place, [with] traffic lights, and people, and noise, and trees" (key informant, 605).

Respect and caring

Especially for people traveling alone, or facing traumatic circumstances, respondents described how providers could offer extra respect and caring for patients who are far from home. One respondent recounted the story of a young woman who had an emergency evacuation from a small community during a high-risk pregnancy. She traveled with nothing and could not get a bag of her own things sent down, thus she relied on donations of toiletries and clothing.

Medical translation

Communicating medical information with providers was mentioned as a challenge for numerous respondents, especially for the 17% whose primary language was not English. Respondents described some benefits and drawbacks of professional translator services compared to having an escort in the appointment.

DISCUSSION

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In this study, medical travelers, escorts, and support workers, were interviewed in the context of a larger project on improving access to healthcare for underserved populations. While Canada's population distribution is unique, jurisdictions within Australia, United States, Norway, Finland, and Greenland have similar geographies that depend on medical travel from remote and isolated communities, and present opportunities for learning. In this population, effective and transparent travel preparation, efficient communication across all phases of care, and cultural knowledge were found to be central to ensuring both access to care and a positive patient experience.

Many medical travelers reported satisfaction with the care received, while also reporting significant stress involved with managing travel logistics across different health jurisdictions. With direct flights from only one NWT community, the first leg involves traveling to the nearest larger centre in NWT, which can add a day or more to the trip, with no designated facility or support for infirm travelers. This 'multi-locality' of individuals moving between home and distant care facilities can become a long-term feature of peoples' lives,(22) creating disruptions to personal, family, community and cultural obligations.(14)

Medical travel can create additional challenges for an already vulnerable person in a health crisis. Almost all NWT residents are required to travel to access advanced medical care at some point.(23) Such travel is further complicated by complex policies affecting healthcare delivery for Indigenous populations.(23) Detailed policies surrounding medical travel and NIHB aim towards standardization, but are not applied uniformly. This may reduce the ability to respond to shifting patient needs in dynamic situations, such as long-distance travel during a period of illness or injury.(22) . Access to information and communication across jurisdictions were particular areas of concern. Electronic health records between NWT and Alberta have allowed for more efficient sharing of patient information, but barriers to full utilization of the system exist and important medical information does not always travel with patients to other jurisdictions.(24, 25) Medical travelers paid out-of-pocket for incidentals and some prescriptions and procedures, and some could not access social assistance benefits or bank accounts away from home. Inter-jurisdiction coordination has been a long-standing challenge, with negative consequences for health outcomes.(22)

Patient escorts were described as an important source of support and advocacy. Family members can support decision-making and adherence to treatment plans,(23) but aren't always the best escorts.(26) Even with changes to the patient escort policy,(22, 26) respondents echoed that challenges still exist, such as unreliable escorts, and inconsistent policy application. For patients alone, a local trained navigator or advocate could help with medical communication, providing emotional and cultural support.(27)

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Communication pre-departure and during the course of travel and treatment should utilize different formats and media to reach a larger audience with targeted information.

Participants called for more culturally appropriate care and cultural knowledge within the healthcare systemChallenges with cross-cultural health communication and health literacy can be particularly harmful.(23, 28, 29) Respondents described the care and support provided by an Indigenous clinic, cultural helpers, and a local northern support unit staffed by healthcare professionals with experience living in remote settings, as extremely valuable. However, not all travelers were aware of or able to connect to services and resources. Recently, culturally-relevant services have been shown to improve the experience of Indigenous patients requiring medical relocation for dialysis in South Australia,(30) and have been identified as especially important for palliative care and cancer services provided away from home in Northern Territory, Australia.(31, 32)

Respondents described the impact of negative healthcare experiences, including not feeling listened to or respected, or discriminated against, on health-seeking behaviours. The unequal patient-provider power dynamic in health care, particularly within a colonialist historical context, is well described.(33-35) Relying on patients to advocate for their health and needed services, underestimates the complex power relationships involved. Eight of the 94 summary recommendations arising from Canada's Truth and Reconciliation Commission specifically pertain to health.(36) Greater understanding of how residential schools, forced relocation and systemic discrimination have shaped Canada's northern communities, and how to use that knowledge to change healthcare service delivery is still needed.

The barriers to medical travel can be overwhelming, leading to delays in receiving care, or an avoidance of care-seeking altogether,(37) resulting in poorer outcomes and higher costs for aggravated health conditions.(38) One study of medical travel in Arctic regions of Nordic countries estimated that the number of service hours per northern patient is 2-3 times higher than urban populations.(39) Continuity of care remains a challenge in the North; with only 31.1% of Indigenous territorial residents seeing a regular doctor, compared to 76.4% of Indigenous people outside the territories.(40) One systematic review of the impact of distance to healthcare services on health outcomes in northern settings found worse health outcomes amongst patients living further away from healthcare facilities and concluded that distance should be a consideration in discussions of treatment options.(37)

To our knowledge, this study is the first to explore the experience of medical travel from the perspective of outpatients, escorts, providers, and support staff in an urban centre in Canada. The mixed-methods design allowed the merging of rich data from multiple different perspectives. One limitation of this study

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is the measurement of patient experience during the medical travel process, and not in the home community following the medical travel journey, which may have provided additional insight into continuity of care. Additionally, while patient travel escorts provided some context for hospitalized patients, respondents were mainly individuals receiving outpatient services, and the study findings may not be generalizable to inpatients with greater acute care needs. Finally, this study conducted interviews at the point of care and did not include individuals living in remote and isolated communities who were not able to get the required appointments, referrals, or the paperwork to travel. Given the potential for delayed or deferred care-seeking, further research is needed to assess the barriers to healthcare access among northern residents who are not able to access medical travel.

The experience of patients travelling a long distance for an extended period away from home is important to understand in order to provide quality care within Canadian provincial health systems, and will be relevant for other jurisdictions serving remote and isolated communities. The majority of medical travelers from NWT were satisfied with the care received. However, many also encountered serious challenges with medical travel, including significant delays in accessing and receiving care. Patients outside of their home jurisdiction are a unique and potentially vulnerable population that could benefit from increased access to and continuity of care. Healthcare providers and policy makers may not be aware of the complexity of the medical travel experience and the stress involved with managing travel logistics across different health jurisdictions. More effective and transparent travel preparation and efficient communication across jurisdictions and with patients could help improve the experience of medical travel for residents of the far north.

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Data sharing statement:

No additional data available.

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Author contributions: SS, FK, KK conceptualized the study, analyzed, and interpreted the data. KK wrote the first draft and all authors contributed to revisions. MO, SL, SJ, SA collected data, and supported analysis and interpretation. ML, MO, MQ SIF, CM, SB, DD, AC contributed to interpretation of results,

writing and review of the manuscript. All authors approved the final manuscript. Each author has reviewed and approved the contents of the submitted manuscript for publication.

Figure caption

Figure 1. A medical travel journey
Figure 2. Satisfaction with most recent healthcare visit
Figure 3. Reasons for medical travel

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Table 1. Self-reported characteristics of study participants, n=52

	N	%
Age group (years)		
18-24	2	3.8%
25-44	11	21.2%
45-64	27	51.9%
65+	12	23.1%
Gender		
Male	29	55.8%
Female	23	44.2%
Ethnicity		
First Nations	20	38.5%
Inuit	10	19.2%
Métis	4	7.7%
Non-Indigenous	18	34.6%
Education (highest level attained)		
Less than high school diploma	19	36.5%
High school diploma	10	19.2%
Some post-secondary	5	9.6%
Post-secondary degree or diploma	18	34.6%

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Table 2. Themes arising from interviews with key informants, medical travelers, patient escorts, and focus group discussions

Opportunities to improve access and experience		**Participant quotes**	**Proposed solutions**
Access to services	(1) Improve information and logistics prior to travel	It's like traveling to a foreign country, like hearing that you're going to go to India tomorrow. You wouldn't even be worried about the procedure; you'd be worried whether all of the things that you've heard are true. What will I eat? Do I have the right clothes? And the airport security? That even makes me nervous. (key informant, 305)	• Increase awareness and distribution of existing medical travel information • Provide information to travelers and medical travel staff on various medical travel scenarios, and what to expect on arrival • Develop user-friendly communication methods and materials regarding itinerary and flight options
		You come inside at the [local university hospital] and there's a big rush. You need to ask someone where reception is…. Some of the reception areas [in the hospital] are bigger than most health centres in the communities. And that's intimidating, especially to older people, Elders. An Elder doesn't want to get lost. (focus group, 352)	
	(2) Increase effective communication between services	The people who are in charge of the medical travel have the power to decide if you are going or not for medical….If the medical travel staff say no, then you don't get sent out…I was told by the Doctor that I needed to go for MRI and I ended up not going and it was never explained why I didn't end up going. (focus group, 351)	• Enhance connections between healthcare providers, administrators and community organizations providing care and support to medical travelers to raise awareness about the various services available • Spread awareness amongst local service providers about medical travel and the services available in home communities and in medical travel destinations
		[My community's] problem is the doctors kept changing month to month. It was confusing patients. One would send for this test; one would send for that test. There was no steady [person]. So when the doctors [in Edmonton] ask, "you got a physician back at home?" you laugh. (focus group, 352)	
	(3) Reduce jurisdictional and bureaucratic barriers	Homecare is not reciprocally billed, and palliative care is not an insured service, and long-term care access is not assured by the contracts that we currently have. … [If a patient from the North is] down here and needs long-term care access, our only resource is to repatriate them to the nearest hospital, and they start the process from the North. This becomes a problem…but we do try to cobble together some things. – (key informant, 120)	• Clarify protocol for out-of-province patients with frontline staff and healthcare providers • Ensure jurisdictional issues do not become barriers to patient care

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Opportunities to improve access and experience		**Participant quotes**	**Proposed solutions**
		…[S]ome of the healthcare professionals get very disgruntled with you if you don't have a [provincial health] card…[We hear,] "No you can't get in to see this particular person because you don't have Alberta healthcare." (key informant, 607)	
	(4) Reduce the financial burden	While back home all the medication was paid for, here we have to wait for reimbursement. I don't understand that some medications you have to pay [for] and not some others. (medical traveler, 3505)	• Ensure that medical travelers are aware of coverage restrictions and policies and have access to funds locally • Communicate potential for out-of-pocket costs associated with care and medications, and provide financial support options for medical travel.
		Sometimes [patients] need to do prep work for appointments, and then they get here and they have to buy this stuff, and have no money, and it's not covered. But if they don't get the prep work they don't get the procedure. (key informant, 305)	
	(5) Provide opportunities for facilitated appointments	The information form I was given [at my consultation] said, "please consider having someone with you post-op." I felt like that wasn't fair because I didn't get to consider that. Medical travel wouldn't allow [an escort]. (medical traveler, 1501)	• Clear communication and adherence to the medical escort policy • Expand the number and scope of patient navigators who can facilitate continuity of care and support throughout a patient's stay, from arrival, to hospital and/or clinics, and back. • Document and disseminate best practices of healthcare navigators
		With the traveling, I would like to see them change the policy with escorts and long term [travel]….I have to travel all by myself because my escort would have to pay her own travel fees. They should allow an escort to come with you regardless if [the escort is] only staying for a week but you are staying for 4 weeks. I have to fly home by myself and it's not easy. (medical traveler, 2501)	
Experience with providers	(1) Increase cultural safety and awareness	There is blatant discrimination and racism all the time. And I don't think people talk about that enough. As a society we push it under the carpet and we don't realize how traumatizing that is to a person. People just don't know about Aboriginal culture and people are not looked at as being on the same level as other people in the country…once you've been on the receiving end of that discrimination you just kind of give up. (key informant, 305)	• Promote the uptake of cultural awareness and cultural safety classes for healthcare providers, frontline staff, and auxiliary staff • Increase community-specific content included in cultural training to provide

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Opportunities to improve access and experience	Participant quotes	Proposed solutions
	[My care would be improved by] doctors understanding where I am coming from: a small town, a long distance, culturally. (medical traveler, 8506)	more information on the specific cultural context for northern patients • Provide outreach opportunities to promote hands-on experiences and cultural learning directly with community members
(2) Facilitate respectful and patient-centred care	I understand it gets busy and stuff like that but we're still human. Each person should still be treated respectfully in any manner. (key informant, 142)	
	Not everybody thinks the same, believes the same or practices the same. So it's having that respect and starting out from a blank page and saying, "let's get to know you." …That's part of the relationship.(key informant, 302)	
(3) Expand access to medical translation and understanding	[The language service does not] have Slavey or Tłı̨chǫ or Inuinnaqtun, Gwich'in. …But how often do we need a Slavey translator? Most people who come who need a translator are Elders anyway and so they would be coming with an escort. The [GNWT] tries to ensure that the escort is comfortable doing this. Sometimes they get someone who is really not suitable. Like you get a 16-year-old coming down with their grandfather with cancer of the rectum. (key informant, 120)	• Ensure that health providers know how to access translation services, including which languages are available through telephone translation • Engage local trained navigators or advocates to support medical communication • Provide travel information as well as health information materials for medical travelers in Indigenous languages
	The language barrier, not so much for me, but other people from Délı̨ne, there's no one who speaks the language. Even the people escorting, their education level isn't that high. So now you have two people lost, trying to find their way to an appointment. My wife's aunt got lost here for a day and a half. She went to an appointment but never made it because she couldn't find it…There's a language barrier especially for the old ones. The Elders have the hardest time of all. (focus group, 352)	

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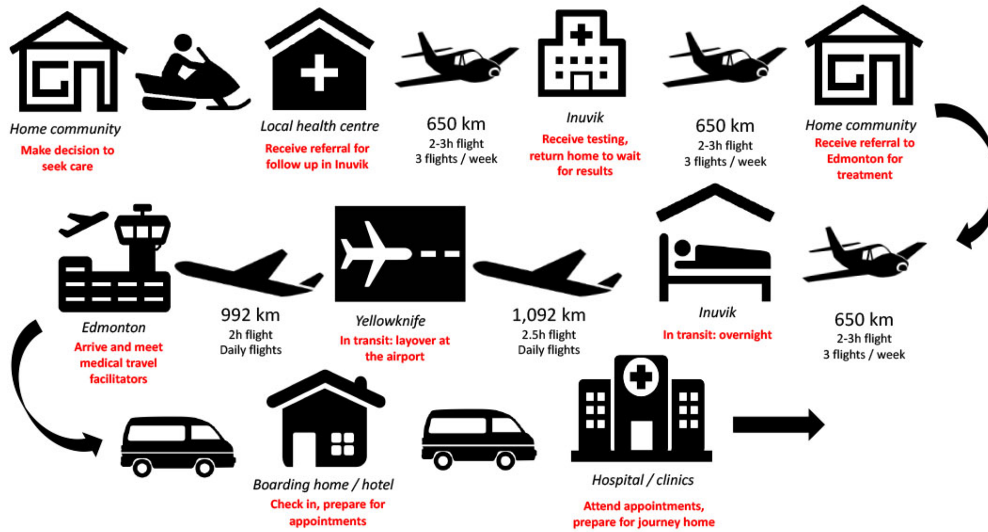

Example of a non-emergency medical travel journey

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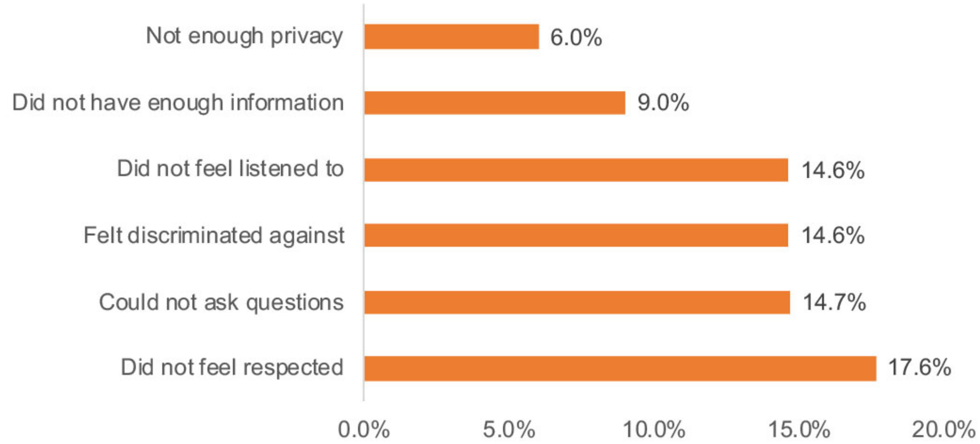

Satisfaction with most recent healthcare experience in Edmonton (n=34)

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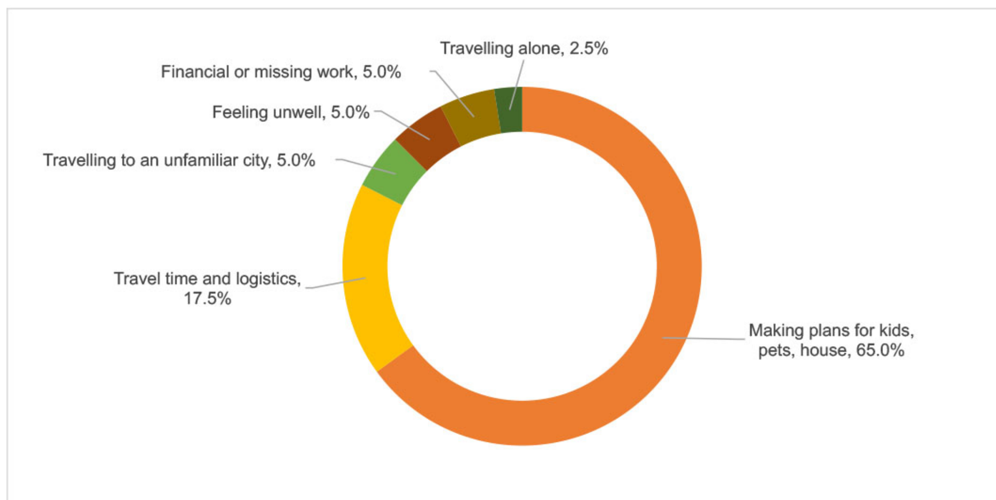

The main difficulty related to medical travel (amongst those who reported, n=40)

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Consolidated criteria for reporting **qualitative studies** (COREQ): 32-item checklist

No	Item	Guide questions/description	Page, line
Domain 1: Research team and reflexivity			
Personal Characteristics			
1.	Interviewer/ facilitator	Which author/s conducted the interview or focus group?	Page 4, line 29-37
2.	Credentials	What were the researcher's credentials? *E.g. PhD, MD*	Page 4, line 29-37
3.	Occupation	What was their occupation at the time of the study?	Page 4, line 29-37
4.	Gender	Was the researcher male or female?	Page 4, line 29, 34
5.	Experience and training	What experience or training did the researcher have?	Page 4, line 27-35
Relationship with participants			
6.	Relationship established	Was a relationship established prior to study commencement?	Page 4, line 36-37
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. *personal goals, reasons for doing the research*	Page 5, line 41-46
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. *Bias, assumptions, reasons and interests in the research topic*	Page 4, line 27-35
Domain 2: study design			
Theoretical framework			
9.	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? *e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis*	Page 5, line 29-37
Participant selection			
10.	Sampling	How were participants selected? *e.g. purposive, convenience, consecutive, snowball*	Page 4, line 40-43; 51-53; page 5, line 16-18
11.	Method of approach	How were participants approached? e.g. *face-to-face, telephone, mail, email*	Page 4, line 40-43; 51-53; page 5, line 16-18
12.	Sample size	How many participants were in the study?	Page 4, line 45; page 5, line 10, 16

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13.	Non-participation	How many people refused to participate or dropped out? Reasons?	Not captured
Setting			
14.	Setting of data collection	Where was the data collected? e.g. *home, clinic, workplace*	Page 4, line 47; 53; page 5, line 16, 20
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?	No.
16.	Description of sample	What are the important characteristics of the sample? *e.g. demographic data, date*	Table 1
Data collection			
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Page 4, line 20
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?	No.
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?	Page 4, line 48; Page 5, line 23
20.	Field notes	Were field notes made during and/or after the interview or focus group?	During; page 5, line 23
21.	Duration	What was the duration of the interviews or focus group?	Page 4, line 47; Page 5, line 13, 21,
22.	Data saturation	Was data saturation discussed?	Page 4, line 45
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	No
Domain 3: analysis and findings			
Data analysis			
24.	Number of data coders	How many data coders coded the data?	Page 5, line 30
25.	Description of the coding tree	Did authors provide a description of the coding tree?	No.
26.	Derivation of themes	Were themes identified in advance or derived from the data?	Page 6, line 42; Page 7, line 49
27.	Software	What software, if applicable, was used to manage the data?	Page 5, line 30
28.	Participant checking	Did participants provide feedback on the findings?	No.
Reporting			
29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. *participant number*	Table 2
30.	Data and findings consistent	Was there consistency between the data presented and the findings?	Table 2

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31.	Clarity of major themes	Were major themes clearly presented in the findings?	Table 2
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Table 2

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STROBE Statement—Checklist of items that should be included in reports of ***cohort studies***

	Item No	Recommendation	Page, Line
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	Title
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	Abstract
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	Page 3; Line 5-40
Objectives	3	State specific objectives, including any pre-specified hypotheses	Page 3; Line 42-49
Methods			
Study design	4	Present key elements of study design early in the paper	Page 4; Line 13-24
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	Page 4; Line 3-36
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up	Page 4; 51-57
		(*b*) For matched studies, give matching criteria and number of exposed and unexposed	N/A
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	Page 5; 3-13
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	Page 4; 51-57, Page 5, 3-13
Bias	9	Describe any efforts to address potential sources of bias	Page 10; 20-29
Study size	10	Explain how the study size was arrived at	Page 4; 55-57
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	Page 5; 3-13

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Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	N/A
		(*b*) Describe any methods used to examine subgroups and interactions	Table 1
		(*c*) Explain how missing data were addressed	Page 5; 3-13
		(*d*) If applicable, explain how loss to follow-up was addressed	N/A
		(*e*) Describe any sensitivity analyses	N/A
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	Reported on each table / figure
		(b) Give reasons for non-participation at each stage	Page 5; 3-13
		(c) Consider use of a flow diagram	N/A
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	Table 1
		(b) Indicate number of participants with missing data for each variable of interest	Reported on each table / figure
		(c) Summarise follow-up time (eg, average and total amount)	N/A
Outcome data	15*	Report numbers of outcome events or summary measures over time	N/A
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	N/A
		(*b*) Report category boundaries when continuous variables were categorized	Table 1
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	N/A
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	N/A

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Discussion			
Key results	18	Summarise key results with reference to study objectives	Page 9-10
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	Page 10; line 19-29
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	Page 10; line 19-29
Generalisability	21	Discuss the generalisability (external validity) of the study results	Page 10; line 19-29
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	Cover page

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