




Patient healthcare experiences in the Northwest Territories, Canada: an analysis of news media articles

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ABSTRACT

The factors that influence patient healthcare experiences are complex and connected to place. In northern Canada, the socio-historical context and the inequitable distribution of health services are unique influences on patients. The objective of this study was to examine the characteristics of patient healthcare experiences as reported through news media in the Northwest Territories. We used a case series design to examine patient healthcare experiences reported in news media articles. We conducted a systematic search for articles published between 2008 and 2017 in the online database of a media outlet in the Northwest Territories. We used descriptive statistics to summarise the article characteristics and thematic analysis to understand patient experiences in 128 articles related to 71 cases. Most often, cases involved women, concerned mental health, suicidality, or chronic diseases, and were predominantly negative. Patient experiences included problems associated with medical travel, communication difficulties with providers, lack of cultural safety, and barriers in accessing care resulting in poor-quality care, particularly for Indigenous patients. Broadly, these experiences are rooted in the colonial history in the North. Understanding patient experiences and including Indigenous patients in health system decision-making can help focus policies and clinical care on cultural safety and equity.

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Background

Increasingly, health systems and providers have recognised the importance of understanding patient experiences in healthcare and the association with health outcomes [1–3]. The factors that influence patient experience are both complex and connected to place [4,5]. Health systems in the Circumpolar North operate in some of the world's least densely populated areas. This global region includes the northern-most areas of the eight Arctic nations, and is the territorial homeland to diverse Indigenous populations. In many of these contexts, health services are inequitably distributed across large geographic areas, with hospital-based care concentrated in regional centres. By consequence, primary and acute care services rely heavily on telehealth, long distance and expensive medical travel, and remotely dispersed providers [6–8].

In the circumpolar regions of Canada, the context, organisation, and outcomes of healthcare are markedly different than in southern and urban regions of the country [6,9].

Many Indigenous communities in the North face systemic barriers in access to mental health and tertiary care in particular [10,11], and experience substantially poorer health status [9,12]. The legacy of colonisation in Canada continues to impact Indigenous peoples, including through discriminatory experiences in the healthcare system [13–15]. Patients may face both overt and subtle forms of anti-Indigenous racism by providers [16,17]. At a systems level, many healthcare organisations do not reflect the Indigenous communities they serve in terms of their core values, conception of health, ways of providing care, governance, or in the composition of their workforce [18]. These structural issues can give rise to the negative social and clinical interactions that Indigenous patients and their families experience, and in turn reinforce health inequities.

Patient experiences and perspectives are increasingly being integrated into healthcare design, delivery, and quality assessment [3,19,20]. A recent scoping review on patient experiences in the global

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Circumpolar North found that factors related to healthcare access including telehealth and medical travel, continuity of care, cultural competency among providers, the ability of patients to speak the language of their preference, the integration of family support, and cultural dimensions of care were all important influences on patient experiences[21]. The review identified only 10 studies from northern Canada, which addressed various experiences related to chronic diseases, mental health, sexual health, in addition to care modalities including virtual care, primary and tertiary care, medical transportation, and cultural competence[21].

Given the context of healthcare in the North, it is important to understand patient experiences and use this knowledge to design and implement systems of care that better address the needs of patients and reflect the values of communities [6,18]. Previous studies provide a valuable starting point for understanding patient experiences in the North, particularly for Indigenous patients. However, these studies are limited because they primarily focused on a specific aspect of care or a specific health condition, or captured a narrow range of perspectives[21]. Overall, there is limited published literature on the topic, and comparatively few studies have taken a systems approach to understanding patient experience in northern healthcare[21].

In recognition of the role of the news media as a common source of information about healthcare [22], we wanted to explore the potential for using online news articles to understand patient experiences. News media, especially newspapers, have previously been used in research about various aspects of medical care [23–25] as well as health and social issues in Indigenous [26–28] and Arctic contexts [26,27,29]. News media articles may be a useful source for patient narratives in the Circumpolar North, and could provide insight into unique challenges and barriers related to patient experiences. The objective of this study was to characterise patient healthcare experiences in the Northwest Territories (NWT) news media. We aimed to describe the demographic and health-related characteristics of reported patient experiences, and examine patient perspectives on their healthcare experiences.

Methods

Search strategy

We used a case series design to examine patient experiences reported in the NWT news media. To identify news

stories, we conducted a systematic search of the online article database for the Northern News Service (NewsNorth), a news media outlet that covers the entirety of the NWT and has select coverage for news in Nunavut [30]. Northern News Service houses a news article archive on its online domain, which allowed for a comprehensive search of articles. Using the SEOquake Chrome plugin restricted to the Northern News Service domain, we conducted exploratory searches to test the sensitivity of several keywords, then reduced our search to the following terms: *health, healthcare, illness, disease, transplant, disability, treatment, clinic, hospital, medical, medicine, and patient*. Our final search took place in June 2018.

An article was considered eligible for inclusion in the study if it met the following criteria:

- (1) the article described a specific healthcare experience of at least one patient;
- (2) the experience related to a patient whose home community was a served by the NWT health system, which includes all the Northwest Territories and the Kitikmeot region of Nunavut; and
- (3) the patient experience was reported in an article published between 1 January 2008 and 31 December 2017.

One author performed the article search from the online Northern News Service archive. Articles that included any one keyword were screened-in for full-text evaluation. Two authors independently reviewed each screened-in article to assess for eligibility. Articles were excluded if they reported on general health or healthcare issues but did not describe a specific patient experience, did not report on patient contact with a healthcare provider or service in the NWT or Nunavut, or were duplicates. When multiple stories covered the same patient experience, we combined information from each story into a single patient experience “case” in order to avoid double counting. Articles were included if both reviewers agreed; disagreements about articles with uncertain eligibility were resolved through consultation with a third author.

Data collection

We developed a standardised data collection form using a spreadsheet to extract information from the articles. Initially, we developed a draft extraction form, then refined it after piloting data extraction with a sample of articles in order to adjust for differences in how information was reported across articles. The fields included in the form were determined prior to the final search and data extraction.

For each patient experience case, we extracted the following information: URL, date of article publication (month, day, year), patient's community of residence, gender (female, male, non-binary), age, health issue, symptom, or diagnosis, health system point of contact (primary, secondary, tertiary), narrative summary of patient experience, and outcome. The majority of these measures varied with respect to how they were reported, for example age would often not be reported numerically, but rather as a category (middle-aged or infant). We created a derived categorical variable to classify the patient experience as positive, neutral, or negative based on the description given by the patient in the article. The outcome variable was based on a national framework developed by the Canadian Institute for Health Information which includes five categories: health status improvement, health status deterioration, health status unchanged, no outcome, and death[31].

Analysis

We analysed the data both quantitative and qualitative approaches. We used descriptive statistics to summarise the characteristics of reported patient experiences. Frequencies and proportions for each characteristic were based on unique patients and not on the number of articles because there were often several articles about the same event or situation. In some cases, each article provided information about patient characteristics or experiences that were not reported in other sources.

To identify themes in the articles, we used a deductive thematic analysis[32]. The coding for this approach was based on a framework developed by Jacklin *et al.* (2017) which highlighted themes related to Indigenous peoples experiences with healthcare[15]. This approach was selected *a priori*, though we adapted it after conducting a pilot analysis on a sample of 10 news media articles. For the purpose of our analysis, we combined the themes of perpetuation of inequities and colonial legacy, and we added an additional theme that emerged around communication in the healthcare system. This modified framework includes four categories for Indigenous patient experiences (Table 1).

Sub-themes in each patient experience were identified using the codes which were determined *a priori*. Two research assistants read each article and applied the coding framework; disagreements were resolved through discussion with a third author. For articles that included more than one patient experience, each experience was coded separately. We quantitatively summarised patient experiences in healthcare and

Table 1. Adapted framework for Indigenous peoples experiences in health care.

Themes	Definition
Perpetuation of inequities & colonial legacy	A patient experience in which broad intersectional inequities and colonial legacy exist and play a role in the patient's quality of care.
Structural barriers to care	A patient experience determined by the geographic location of the patient and/or discrepancies in policy and/or services.
Positive healthcare experience	Characterised by an experience that supports patients in their care plan through collaboration, support and respect for cultural beliefs and practices, and meeting patient expectations for providing appropriate health services.
Healthcare system communication	A patient experience characterised by ineffective communication in the healthcare system that leads to a perceived discrepancy in quality of care.

described the experiences of healthcare based on the analytical framework. This study did not require research ethics board approval because it was based on publicly available information.

Results

The search yielded 430 articles. After removing duplicates (articles with iterations) and ineligible articles ($n = 302$), the final dataset contained 128 articles related to 71 patient experience cases (Figure 1). The distribution of unique patient cases and articles over the study period is shown in Figure 2.

The majority of patients were from the NWT, and from Yellowknife specifically (Table 2). Females accounted for a half of all patients, as did adults between 19 and 59 years old. Mental health and suicidality were the most prevalent primary health conditions or issues reported in the articles. Patients and family members provided the predominant perspectives (Table 2). Justice system involvement was reported in five patient cases, three of which related to RCMP response to a mental health issue. Aeromedical evacuation ("medevac") or other issues related to medical travel such as a lack of funding for family escorts was reported in 46.5% of the patient cases; medical travel was a concern in significantly more patient cases in small, remote communities compared to the territorial capitals, Yellowknife, and Iqaluit, (70% vs. 29.3%, $p = 0.001$).

Types of patient experiences

The articles included a range of patient experiences that fit into the analytical framework (Table 2).

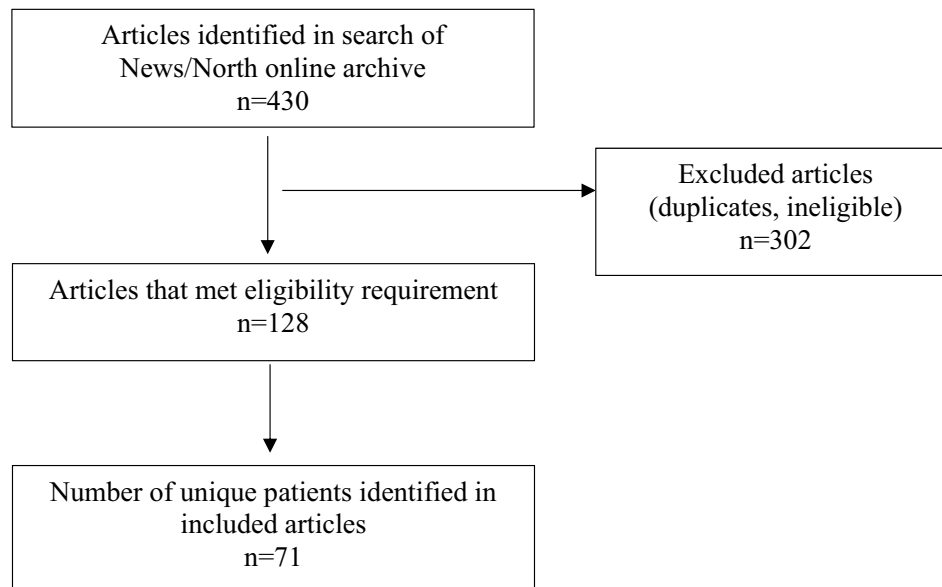


Figure 1. Article selection process.

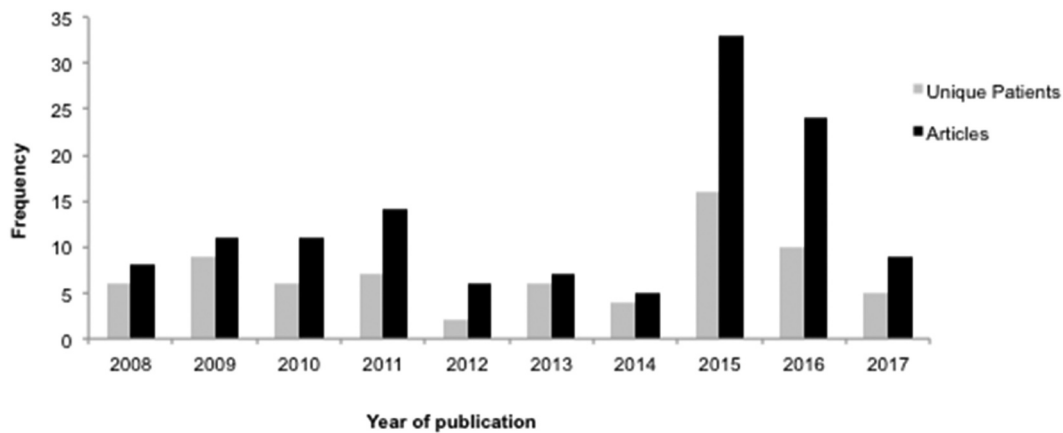


Figure 2. Distribution of news media articles about patients' experiences in northern Canada, 2008–2017 ($n = 128$).

Overall, there were 177 types of patient experiences deduced from the thematic analysis. Among the 71 patient cases, articles described three different categories of patient experiences for 29.6% ($n = 21$) of cases, 30.9% ($n = 22$) had two or more categories, and 39.4% had one category of patient experience.

Structural barriers to care

Patient experiences with structural barriers to care were the most commonly reported type of experience, occurring in 76.1% of the cases ($n = 54$). Concerns about medical travel such as a lack of funding for escorts to accompany patients on trips to regional centres or to tertiary care, and experiences with substantial delays in arranging emergency medical transportation were repeatedly noted (Table 3). Patients also described the financial

burden of frequent and extended medical travel, as well as the negative impact of medical travel on family and social relationships. Patient experiences related to limited local access to services and treatments, and jurisdictional issues around funding were also emphasised.

Perpetuation of inequalities and colonial legacy

Perpetuation of inequalities and colonial legacy in health care appeared in 50.7% of patient cases ($n = 36$). Examples included patients being denied specific services, treatments, or travel funding, or experiencing anti-Indigenous racism when presenting to hospitals and clinics for care (Table 3). Patients and their families often reported perceptions of poor-quality care.

Table 2. Patient characteristics from news media articles on patient healthcare experiences in the Northwest Territories, 2008–2017.

	Frequency, N = 71	%
Territory		
Northwest Territories	57	80.3
Nunavut	14	19.7
Community of residence		
Yellowknife	37	52.1
Hay River	5	7
Iqaluit	4	5.6
Other territorial communities*	25	35.2
Gender		
Female	36	50.7
Male	32	45.1
Non-Binary	1	1.4
Not Reported	2	2.8
Age Group		
≤ 18 years	11	15.5
19–59	36	50.7
≥ 60 years	17	23.9
Not reported	7	9.9
Primary health condition or issue		
Suicidality or mental health	12	16.9
Cancer	8	11.3
Circulatory	8	11.3
Digestive	6	8.5
Genitourinary	6	8.5
Injury	6	8.5
Respiratory	5	7
Obstetrics/Neo-natal	3	4.2
Geriatrics	2	2.8
Infectious	2	2.8
Nervous System	2	2.8
Other	8	11.3
Not reported	3	4.2
Outcome		
Death	17	23.9
Deterioration	11	15.5
Improvement	16	22.5
Unchanged	5	7.0
No Outcome reported	22	31.0
Primary source in article		
Patient	30	42.3
Family member	26	36.6
Health Official	11	15.5
Police	1	1.4
Advocate	2	2.8
MLA	1	1.4

* in NWT or Nunavut communities with a population of <3,500; NWT: Northwest Territories; MLA: Member of the Legislative Assembly.

Health system communication

Concerns about health system communication were evident in 39.4% of cases (n = 28). Patients identified experiences related to challenges with sharing information between providers from different disciplines and systems, such as between physicians and pharmacists, or the health system and the justice system (Table 3). A lack of communication between care providers and families was often noted, with several examples of patients experiencing suicide-related risks being discharged from hospital without notifying family members. Several articles described communication problems in the health system in which patients got “lost in the shuffle.” Elders in particular appeared to

experience language barriers, and had a difficult time communicating with providers (Table 3).

Positive healthcare experiences

Articles most often reported negative patient experiences, however nearly a quarter of patient cases (22.5%, n = 16) included descriptions of positive patient interactions in the healthcare system (Table 3). Patients commented on experiences such as quick referrals and follow-up for diagnoses at tertiary centres, expanded access to services and treatments such as dialysis, and the use of telehealth to avoid disruptive and time-consuming medical travel for routine follow-up. There were also examples about efforts to include connections to community and culture as a part of therapeutic milieu by supporting patient contact with Elders and participation in cultural healing activities.

Discussion

Across Canada, health systems have begun to integrate patient experience as a central aspect of healthcare quality and as a priority in healthcare delivery[33]. We used a case series design to examine patient experiences in the North based on online news articles. Our results indicated that news media articles provide insight into the unique aspects of patient healthcare experiences in a northern context. Patient healthcare experiences reported in news media frequently involved problems associated with medical travel, communication difficulties with providers, systemic barriers to access that resulted in unmet needs or poor-quality care, and a lack of cultural safety.

Overall, the patient experiences described in this study aligned with previous studies from the region [11,34,35] and with the experiences documented in other Indigenous contexts [15,16]. Patient experiences often involved structural inequities in access to health services and the consequences of poor-quality care among First Nation, Metis, and Inuit patients in the North. In part, this reflects the demography and social context of the territory, with 50.7% of the population in the NWT being Indigenous. The extent of problematic and discriminatory patient experiences in healthcare also reflects the reality that the health systems in the North continue to be shaped by the legacies of colonisation [34,36].

Our analysis provides further evidence that medical transportation is a major factor in patient experience of healthcare in the North [8,11,35]. Nearly half of all patient cases included concerns about the medical travel for patients from northern communities. Medical travel is one of the ways that rural and circumpolar

Table 3. Summary of themes and patient quotes from news articles.

THEME	Example from article
Perpetuation of inequities and Colonial Legacy	
Colonial legacy of health care	"When people have painful experiences dealing with the government, whether it's in a labour relations matter or whether it's in respect to health-care delivery, wherever it is, it's hard for people to trust that anybody looking into that will understand the nature of that mistrust and that pain" "[t]here is such a strong element of racism in the health system, and it's more apparent in some regions than in others"
Denied appropriate care	"It wasn't necessary. It should not have gone that way. Would he have died anyway? We all don't know that and it's a moot point because he was never seen." "I told the doctor that was discharging me, she's giving me a prescription for pills and I'm going to pick up those pills and take them all at one time ... I told her I was going to hurt myself and she didn't have me committed."
Perceptions & experiences of poor quality care	"I didn't receive the help right away I needed. It didn't have to take so long, I don't want other people to go through that." "I believe that when my son entered the ambulance in the state that he was in, he became the responsibility of the [health system] ... He should have been kept safe. They knew his mental condition but neglected to deal with it adequately."
Lack of respect for cultural practices	"I have a problem and I attempted to fix it, and the health care system failed me when I demanded help." "I know that the health professionals are always helping us with our needs, but when it comes to low-risk birthing, those of us birthing at home both in Iqaluit and in the communities, those of us are not given the opportunity to practise our Inuit ways of birthing"
Healthcare system communication	
Breakdown in communication	"Too often, patients are denied a medical escort only to get to the hospital to be asked where their escort is" "There was no face-to-face. The doctor calls and says you have this kind of cancer. To hear that on the telephone was terrifying"
Lack of communication	"The perception is that we have a medical system where all parts of the system are talking to each other but they're not. Partly because of the privacy act but also because of the way the services are divided" "I went inside at emergency and the nurse said, 'What are you doing here?' I said, 'Did anybody call you from the Norman Wells health centre?' ... They said nobody from the Norman Wells health centre notified them that I was coming." "The health-care system has been really hard to navigate ... A lot of the different areas that we've been dealing with, they don't talk to each other and they don't give us the resources to access a more full spectrum of care."
Language barrier	"She likes to be able to speak to the doctors to tell them what her problems are but she can't speak (English). She has a hard time ... Sometimes when they don't have a translator they just tell her to come back" "My wife doesn't speak good English or read, and there is no one to help her with how to take her medication."
Positive healthcare experience	
Access to appropriate healthcare services	"For us, having to go with a three-month old baby all the way to Alberta for a five-minute consult, it just made a lot more sense to do it through telehealth."
Desired outcome achieved	"They're willing to let me stay here as long as the government here can have a plane ready when they call"
Healthcare provider-patient collaboration	"The staff all know each other [at the seniors home], we know the residents by first name, they're not numbers. We really do care"
Structural barriers to care	
Geographic isolation	"I haven't been home since January ... What makes it harder is I have three other kids at home" "I wanted to be with my son too, to give him support, but we just can't afford to fly over there ... It's pretty expensive when you're a pensioner. All of us wanted to go to be by his side and give him support, we just can't afford it."
Health policy and funding	"[Patients are] busy fighting their disease, it's not fair to make them fight the bureaucracy at the same time. Delaying their coverage and leaving them in the dark over whether they will be covered is just an added burden." "She was killed by the system"
Healthcare services shortage	"There are challenges to recruiting talent to the North ... trying to find people who want to come up here and commit long term is never easy in any of the medical specialities or fields." "There's a long, long waiting list. I don't want to be the whiner and complainer, but I said, 'We're going to try and keep my mom in her house another year' and they said, 'Oh boy, you've got to get going on this paperwork application. It can take up to two years'"
Lack of appropriate services	"I don't think people are getting the full services who actually need them. It's not a luxury, it's just simple basic services that are needed." "I knew I was suffering from a really bad bout of depression and I needed resources. I needed help and it wasn't there"
Lack of continuity in care	"In mental health, moving from counsellor to counsellor to counsellor, even in the same system, is difficult." "When he was in the paediatric system he received excellent supports ... Now all that investment for all these years is lost. Not only for our family but for the education and the medical system."

health systems cope with the inequitable distribution of services. However, medical travel in northern Canada is costly for both the health system and individuals, and is disruptive for families because it interrupts employment, childcare, and school.

A recent qualitative study identified strategies for improving medical travel experiences for northern residents such as better connecting patients with support services in referral centres and increasing culturally appropriate communication[35]. Patient reports in our

study emphasised the value of using telehealth to prevent non-urgent travel, especially for routine follow-up appointments. Patients indicated increased resources to support extended relocations to regional and urban centres for care may also be a useful and economical way to decrease travel costs.

In the future, a better understanding of patient experiences can help inform health system transformation in the Northwest Territories and Nunavut. As this study highlights, patients report a range of complex and at times harmful experiences in healthcare, which were often related to circumstances that are specific to northern communities. However, knowledge about what it is like to be a patient in the NWT will not directly or independently lead to meaningful and equity-oriented reforms in healthcare, in either the North or elsewhere. Accelerating efforts to understand and measure patient experiences, must be bolstered by substantive actions to include patients in health system redesign. System-wide efforts to integrate patient and community perspectives and governance in healthcare may help improve both patient experiences and outcomes.

Although previously there were efforts to measure patient healthcare experience in the NWT, recently the territorial government began using online patient surveys to seek feedback related to satisfaction, treatment, preventative health, and safety[37]. This is an important step that can be complemented by methods such as in-depth interviews and focus groups to better capture diverse and nuanced patient experiences [20] which are more specific and fundamental to patient care in northern Indigenous contexts.

In the Circumpolar North, issues related to cultural safety and racism, provider relationship and continuity, access to traditional medicines and ceremonies, barriers to primary care, and medical travel are critical elements of patient experiences [10,11,34,35]. Our study underscores the need to include these dimensions in health system efforts to understand patient experiences, such as standardised patient surveys. Relatedly, the capacity to undertake extensive investigations about patient experience may be limited in northern health systems, and compounded by the time and cost required to make meaningful use of the information once it has been collected[20].

The use of online news articles for research was feasible and provided an overview of the types of encounters and relationships patients experience. As a secondary data source, news media articles are prone to several sources of bias. However, the value of this approach, as has been shown in similar studies [26–28], is that it provides timely and accessible information at low cost, and therefore overcomes many of

the barriers that are common in northern research. In the future, scaled-up efforts to understand patient experiences undertaken by northern health systems and researchers would be strengthened by collaborative and community-based studies about the social, cultural, and historical context of care[21].

Strengths and limitations

The study was limited to the patient experiences reported in NewsNorth media articles and does not capture patient experiences that may have been reported through other media sources such as the national broadcaster, Nunavut-based media, or community radio. As a result, the capture of articles specific to patients from Nunavut was incomplete. As well, news media reports are a secondary data source; the primary information gathering was not done for research purposes.

Evidence suggests that the news media increasingly report negative health experiences[38], which could have introduced negativity bias. Relatedly, we did not use an inter-coder reliability test for the classification of patient experiences as positive, neutral, or negative. Rather, we reached consensus on the classification of each article between the two authors who conducted the analysis; disagreements we resolved through consultation with a third author.

News media reports on health experiences that are viewed by patients as being important to share, therefore, systematically compiling these experiences allows us to gain insight into what healthcare system issues are of relevance to patients. This study is strengthened by our use of both quantitative and qualitative summaries of patient experiences.

Conclusion

Patient experiences are commonly reported in news media in northern Canada. Experiences of care related to mental health and suicidality were the most frequently described, and challenges related to medical travel, especially for patients in small and remote communities, were consistently identified. Many of the patient experiences reported in news articles highlighted problematic aspects of healthcare in the North, including experiences of discrimination and structural inequities. The media review method captured patient experiences not described in current patient experience surveys. This study provides insight into the experiences of patients in a circumpolar region of Canada by underscoring the complexities of place and context in shaping healthcare experiences.

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