BMJ Open Patient experience studies in the circumpolar region: a scoping review

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ABSTRACT

Objectives Patient experiences with health systems constitute a crucial pillar of quality care. Across the Arctic, patients' interactions with the healthcare system are influenced by challenges of access, historical inequities and social determinants. This scoping review sought to describe the range and nature of peer-reviewed literature on patient experience studies conducted within the circumpolar region.

Design In a partnership between Danish/Greenlandic, Canadian and American research teams, a scoping review of published research exploring patient experiences in circumpolar regions was undertaken.

Data sources Seven electronic databases were queried: MEDLINE, Embase, Scopus, 'Global Health 1910 to 2019 Week 11', CINAHL, PsycINFO and SveMed+. Eligibility criteria Articles were eligible for inclusion if

they (a) took place in the circumpolar region, (b) reported patients' perspective and (c) were focussed primarily on patient experiences with care, rather than satisfaction with treatment outcome.

Data extraction and synthesis Title and abstract screening, full-text review and data extraction was conducted by four researchers. Bibliometric information such as publication date and country of origin was extracted, as was information regarding study design and whether or not the article contained results relevant to the themes of Indigenous values, rural and remote context, telehealth and climate change. Two researchers then synthesised and characterised results relevant to these themes.

Results Of the 2824 articles initially found through systematic searches in seven databases, 96 articles were included for data extraction. Findings from the review included unique features related to Indigenous values, rural and remote health, telehealth and climate change. **Conclusions** The review findings provide an overview of patient experiences measures used in circumpolar nations. These findings can be used to inform health system improvement based on patient needs in the circumpolar context, as well as in other regions that share common features. This work can be further contextualized through Indigenous methodologies such as sharing circles and community based participatory methods.

INTRODUCTION

A growing body of research exploring patient experiences of care reveals that such measures not only capture level of satisfaction with care but also correlate with important

Strengths and limitations of this study

- ► This scoping review represents the most comprehensive and detailed examination of existing literature on patient experiences in the circumpolar region
- Our focus on four core features of circumpolarspecific patient experiences (Indigenous values, rural and remote, climate change and telehealth) provides a clear view of experience domains relevant to circumpolar populations, while allowing bottom-up synthesis of themes.
- A potential limitation of this study was that no external framework was used to guide data analysis, which limits the ability of these findings to dialogue directly with research in this field.

metrics including clinical outcomes and patient safety.¹ Targeted attempts to improve patient experiences have led to quantitative improvements in health outcomes.² Additionally, positive patient experiences have been linked to high satisfaction among medical teams-a critical factor in the prevention of burnout and workforce attrition.³

The experiences of patients in health systems can be reflective of the challenges and privileges they experience in daily life. Racial and ethnic minorities, as well as rural and low-income populations continue to experience suboptimal health outcomes, due in part to the effect of institutionalised racism and structural poverty on their ability to access and receive quality healthcare.⁴

Residents of the circumpolar North face these challenges as well, and while some northern populations compare favourably with the respective national average in terms of mortality rate for conditions such as diabetes, the relatively high rates of other conditions including heart disease and selfinflicted injury indicate significant disparities in health promotion and utilisation in the circumpolar North.⁵ Furthermore, the unique characteristics of the circumpolar region make the provision of quality healthcare especially challenging. Huot et at^{β} previously identified four themes that were unique to access to care in northern health systems: influence of physical geography, provider-related barriers, culture and language and the impact of systemic factors such as lack of funding.

A number of studies address similar themes, including one study of Sami patients in the Norwegian healthcare system that found a culturally unsafe environment and lack of interpreting services to be associated with patients receiving unequal access to health information.⁷ Additionally, a study involving First Nations, Inuit and Métis participants in Canada showed how the legacy of colonialism as well as contemporary exposures to culturally unsafe care impacted how engaged patients felt with their diabetes management.⁸

The circumpolar region is home to many Indigenous populations, where the unique historical, environmental and cultural dynamics contribute to the complexity of system-wide evaluation of patient experiences in the region. The predominant approaches to health system evaluation are rooted in a biomedical conception of health, though other approaches, such as postcolonial and traditional knowledge ideologies are beginning to become incorporated into mainstream health systems analysis.^{9–13}

Another defining feature of the circumpolar world is its sparse population distribution and the predominance of communities situated in remote areas. This presents challenges to the provision of safe and accessible healthcare. One study of rheumatoid arthritis patients in rural Canada found that travel distance as well as severe weather affecting travel negatively impacted their healthcare experience.¹⁴ However, the challenge of geographical remoteness also stimulates innovation; circumpolar areas are renowned for their pioneering implementation of telehealth technologies.¹⁵ Expanding use of telehealth for services such as chronic disease management¹⁶ and diagnostic imaging¹⁷ holds the potential for transformative health system changes, but it also brings with it novel barriers to the assessment of patient experiences. The increasing reliance on telehealth in circumpolar regions necessitates a review of patient experiences using these technologies.

The aim of this scoping review was to describe patient experience studies conducted within the circumpolar region, with the goal of elucidating factors that influence patient perceptions and utilisation of health services.

METHODS

A scoping review with a thorough systematic search and screening process was conducted. Though the search was planned in advance, no protocol was registered. Our methodology was informed by the scoping methods devised by Arksey and O'Malley¹⁸ and as such, our goal was to provide a broad overview of the extent and range of literature relevant to patient experiences in circumpolar populations. Scoping reviews have been successfully used to better understand health topics in circumpolar regions.^{19–21} Our work does not assess the quality of included articles, but aims to provide a preliminary picture of what has been published across Arctic regions with shared experiences. In this review, analysis was conducted across dimensions of patient experiences related to the shared features of Indigenous values, rural and remote geography, climate change and telehealth, as these categories are of particular importance to circumpolar health systems given the specific challenges and characteristics of the circumpolar region. Publications that did not address these categories were still included. This allowed for broad capture of relevant publications and bottom-up synthesis of themes.

Patient and public involvement

No patient involved. Patient engagement in future phases is discussed in the conclusions.

Focus population

The focus population of the review was the population living in the circumpolar region, which is home to many Indigenous populations.²² The circumpolar region was defined geographically by definitions used in an international circumpolar health systems comparison.¹⁵ Additional regions considered circumpolar were made based on Indigenous regions represented through international forums such as the Arctic Council.²³ A circumpolar health sciences librarian made some alterations to the boundaries used for circumpolar geography in the search (figure 1).

Search strategy

Preliminary searches were conducted by both the American/Canadian team and the Danish/Greenlandic team, before combining search terms and refining them in collaboration with the librarians. This lead to a comprehensive search syntax based on the two key concepts, namely 'patient experience' (searched in 'all fields') and 'circumpolar region/population' (searched in 'title, abstract and keywords'). The full search strings are available in online supplemental file 1.

Searches in seven electronic databases were conducted on 27th March 2019: MEDLINE, Embase, Scopus, 'Global Health 1910 to 2019Week 11', CINAHL, PsycINFO and SveMed+. Only in the database SveMed+ a small adjustment of the search string was necessary to be applied in the search machine. The search had no limited time frame.

Screening and selection process

The search result of the databases was imported to the online review programme Covidence,²⁴ where duplicates were screened and excluded by the programme and an additional hand-search for duplicates was performed. The whole screening process of the review was conducted in Covidence by four researchers under the supervision of two senior advisors.



Figure 1 Map of the circumpolar North and its regions. Map by Winfried Dallmann, Norwegian Polar Centre.

Eligibility criteria were developed for the title and abstract screening, and refined for the full-text screening. In the title and abstract screening, articles were eligible if:

- a. Study participants included northern or Indigenous populations.
- b. Studies reported the patient perspective.
- c. Studies on all areas of patient experiences in the healthcare system from a specific illness to health promotion activities, excluding perceptions of health research and specific treatment outcome.

For the full-text screening criteria were made more explicit, and articles were excluded if:

- a. The study did not take place in the circumpolar region or focus specifically on care experience of circumpolar population.
- b. Less than 5% of study participants were from the circumpolar region.
- c. Patient experience pertained to outcome rather than care experience.
- d. The study failed to directly measure patient experiences.

In the full-text screening, the full-text of 10 articles were not accessible, and original authors and journals could not be reached, therefore these articles were excluded.

Extracted data included bibliometric information, study design, method, location, reason for seeking treatment, general themes from each article and whether or not the article had a focus in Indigenous values, rural and remote geography, climate change, and telehealth. These latter categories were selected because of their special relevance to the health experiences of circumpolar populations. Two independent librarians conducted an external validation of the literature search. Each article was reviewed at every stage of screening by two of the four reviewers. Extracted information to the Excel sheet was also reviewed by a second person in the review team. The screening and selection process are visualised in the PreferredReporting Items for Systematic Reviews and Meta-Analyses (PRISMA) diagram in figure 2, and a corresponding PRISMA checklist was completed during review (see online supplemental file 2).

RESULTS Bibliometric results

A total of 96 peer-reviewed articles were identified. The oldest study on patient perspectives and experiences included in this review dates back to 1989.²⁵ The number

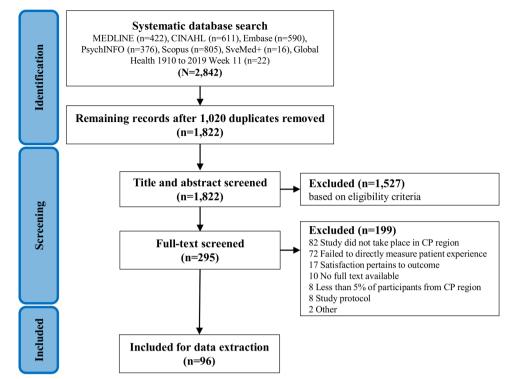


Figure 2 PreferredReporting Items for Systematic Reviews and Meta-Analyses (PRISMA) of the screening process. CP, circumpolar.

of patient experience studies roughly doubled each decade thereafter (table 1). Three quarters of the studies took place in Iceland (n=24),²⁶⁻⁴⁹ Norway (n=24)⁴⁹⁻⁷² and Sweden (n=22).^{17 47-49 73-90} Nineteen studies were from North America; Canada (n=10)^{25 91-99} and Alaska (USA) (n=9).^{16 100-107} Five or less studies took place in Finland (n=5),⁴⁷⁴⁸¹⁰⁸⁻¹¹⁰ Greenland (n=4),¹¹¹⁻¹¹⁴ Russia (n=3)¹¹⁵⁻¹¹⁷ and the Faroe Islands (n=1).¹¹⁸ Three articles included study results from more than one country.⁴⁷⁻⁴⁹ Half of the identified studies applied a quantitative research design with surveys as their only data collection method (n=47).¹⁷²⁶⁻³⁶⁴⁷⁵⁰⁻⁶²⁷³⁻⁸³⁹¹⁹²¹⁰⁰⁻¹⁰²¹⁰⁸⁻¹¹⁰¹¹⁵¹¹⁶ Forty articles

Table 1 Bibliometric results of included articles						
Year of publication		Country of study		Study design		
2010–2019	52	Iceland	24	Quantitative	47	
2000–2009	27	Norway	24	Qualitative	40	
1989–1999	17	Sweden	22	Mixed- methods	9	
Language of article		Canada	10	Methods applied in study		
English	87	Alaska (USA)	9	Survey	56	
Norwegian	6	Finland	5	Interview	40	
Danish	1	Greenland	4	Focus groups	9	
Icelandic	1	Russia	3	Text analysis	6	
Finnish	1	Faroe Islands	1	Participant observation	3	

applied a solely qualitative research design of which 29 used only interview as a method, $^{37-43\,48\,63-70\,84-86\,93-97\,103\,104\,111\,112\,118}$ 6 applied only focus group discussions (n=4) $^{16\,44\,71\,117}$ or text analysis (n=2) $^{87\,105}$ as a method and 5 studies applied various qualitative methods. $^{25\,88\,98\,113\,114}$ Nine studies applied mixed methods (mix of quantitative and qualitative methods) of which six used a combination of a survey and interviews, $^{46\,72\,90\,99\,106\,107}$ two survey and text analysis $^{49\,89}$ and one survey and focus group discussions. 45

Quantitative studies were the most commonly used study design in Sweden (n=13),^{17 49 73–83} Norway $(n=13)^{50-62}$ and Iceland (n=12),^{26–36 49} and less than half of the studies in these three Scandinavian countries applied qualitative methods (figure 3). Qualitative methods were largely found in Alaska (n=4),^{16 103–105} Canada (n=7),^{25 93–98} Greenland $(n=4)^{111-114}$ and the Faroe Islands (n=1).¹¹⁸

The identified studies were further categorised into the different disease groups based on the focus or included patient group in the studies. Nearly one-fifth of the studies did not focus on a specific illness and were categorised as general (figure 4). These general studies typically took the form of a patient experience survey sent to a random sample of citizens or patients in a particular region or hospital network (n=18).^{25 55 57 64 73 87 89 97-102 104 109 111 115} Other common areas of patient care where patient experience studies were conducted were in maternal health (n=13),^{28 33 37 48 49 76 78 79 90 93 105 112 116} primary health-care (n=12),^{16 17 36 40 54 56 59 74 77 82 83 95} mental health and addiction (n=9),^{41 46 58 66 67 80 91 110} cancer (n=8),^{3438 39 50 103 106 113 114} emergency (n=8)^{3035 75 85 88 94 108 118} and surgery (n=6).^{26 47 52 60 65 70} Less than five studies were

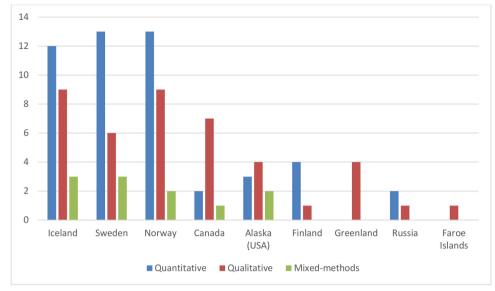


Figure 3 Country by study design (n=102), 3 of the 96 studies included three countries.

identified in each of the remaining nine areas (figure 4). Studies of primary healthcare, surgery, pain, headache and paediatric issues were more likely to use quantitative methodologies whereas studies of cancer, geriatric health, diabetes, disability and pharmacy issues were more likely to rely on qualitative methodologies (figure 4). Studies of general health issues, maternal/child health, mental health/addiction, emergency and communicable disease used quantitative and qualitative methodologies in approximately equal measure. See also online supplemental file 3 for extraction table and detailed overview of the articles.

Thematic results

Over half of the included articles (n=49) did not focus on any of the four predefined categories that were thought to be characteristic of circumpolar health systems: Indigenous values, rural/remote health, climate change or telehealth. Figure 5 and figure 6 provide an overview of the 47 articles that account for findings valuable to the circumpolar-specific patient experience categories. The remaining studies related to patient perspectives and experiences with healthcare services were included in the general analysis of patient experiences studies.

It was noteworthy that every Canadian and Greenlandic article contained at least one predefined circumpolar patient experience factor: Indigenous values, rural and remote healthcare, climate change or telehealth. Seven out of 9 articles from Alaska (USA) (77%),^{16 100-102 104 106 107} 16 out of 24 articles from Norway (67%),^{49 55-62 66-72} 2 out of 5 articles from Finland (40%),^{109 110} 1 out of 3 articles from Russia (33%),¹¹⁷ 6 out of 22 articles from Sweden (27%),^{17 81-83 87 90} and 2 out of 24 articles from Iceland (8%),^{44 45} contained at least one of these factors, while the article from Faroe Islands

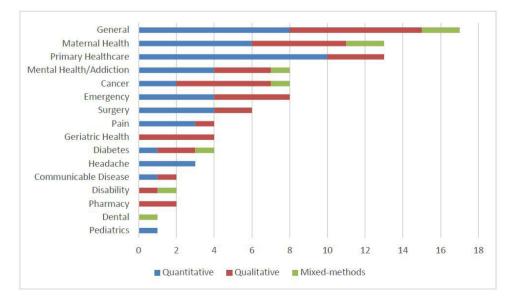


Figure 4 Reason for seeking care by study design (n=96).

Telehealth	Rural/remote	Indig. values	Climate change
4	15	6	-
	7		3
	8		

Figure 5 Studies containing one or more of the four predefined categories (n=47)

contained none of the factors. Of the predefined circumpolar issues, rural and remote healthcare was the most commonly captured factor (n=36), 16 17 25 44 45 $^{55-57}$ $^{59-62}$ 66 71 72 81 90 91 $^{93-102}$ 104 106 107 $^{110-112}$ 114 117 followed by Indigenous values (n=21), 16 25 58 59 $^{67-69}$ 71 82 92 $^{94-99}$ 107 $^{111-114}$ telehealth $(n=13)^{16}$ 17 $^{60-62}$ 70 72 83 87 90 99 109 110 and climate change (n=3). 95 96 107 Results relevant to the four predefined themes are summarised below.

Rural/remote and telehealth

Receiving care in one's home community, geographical proximity and the possibility to save costs and time for not having to travel to urban areas for healthcare services, were aspects important to positive patient experiences. ¹⁶ ¹⁷ ⁴⁴ ⁵⁵ ⁵⁶ ^{60–62} ⁷² ⁹⁰ ⁹³ ¹⁰⁰ ¹⁰⁴ ¹⁰⁶ In the 13 studies investigating patient experiences with telehealth, patients responded that telehealth had obviated the need for travel or that even if telehealth had limitations, they would still prefer teleconsultation from having to travel far distances. ¹⁷ ⁶⁰ ⁷² ⁸³ ⁹⁰ ¹⁰² ¹¹⁰ One Swedish study found that patients experienced that the waiting times for telehealth calls were too long, ⁸⁷ while a study in Finland found that patients felt they cut waiting time and were enabled to access quality care faster. ¹⁰⁹

Experiences with telemedical devices were diverse among the identified studies. Three studies noted that patients appreciated the presence of more than one health worker in the consultation, which gave them the experience of a more thorough consultation.^{60 62 70} Patients in other studies doubted professionals' ability to diagnose certain diseases without physical contact.^{16 90} They were in some cases able to follow the examination on the screen,^{60 70} while others were uncomfortable appearing on the screen.⁶⁰ Negative experiences with telemedical consultations were linked to not being able to build a personal relationship with the professional on the other side of the screen^{16 70} or participants in the consultation not introducing themselves.^{90 109} Lastly, some studies on satisfaction with telehealth consultations found that patients saw further potential if technology was improved.^{16 90}

Negative patient experiences or issues related to receiving care in urban areas despite having to travel far were unstable or lack of physician coverage, $^{55-57, 59, 95, 106}$ perceived disparities in accessibility to high quality health-care in rural regions, $^{25, 45, 91, 101}$ limited services offered in rural areas, $^{55, 71, 95, 104}$ poor continuity in care or not being able to build a relationship with the provider lead to insecurity among patients and thereby decreased use of health services, 81 lack of accommodation for patients and family members when treated in urban areas, $^{94, 98, 102}$ and being overwhelmed and disoriented when travelling to unknown urban areas.

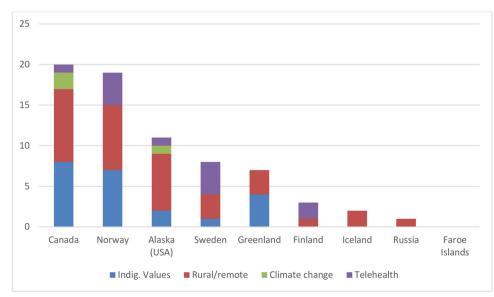


Figure 6 Country by category (n=47).

The 15 qualitative studies gave more nuanced patient experiences. Studies from Greenland and Canada with Inuit patients found that not being treated in their home community gave patients the feeling of being isolated and cut-off, as well as feeling out of their natural rhythm and tradition.^{94 95 99 104 111 112 114} In one of these studies this was also associated with the context of colonial history.⁹⁹ Having to leave one's family and life in order to access care also lead to destabilising situations such as patients missing work.^{95 112} Not having immediate access to services made patients in rural areas feel unsafe.⁹⁵ Levels of trust that rural patients felt towards local healthcare workers varied across different studies, with some patients worrying about the risk of gossiping in small communities.^{66 93 95-97} A study from Russia assessing the diagnostic delay of tuberculosis found that patients in rural areas described physicians to not be equipped with the competencies required for practice in the region, and they did not expect 'good doctors' wanting to serve their communities, which influences their choice of accessing care.¹¹⁷ Another remote challenge in relation to healthcare discussed, was the difficulty of being able to access healthy food, which often was a recommendation or part of a treatment given by physicians.^{96 107}

Indigenous values and climate change

A majority of the studies presenting aspects related to Indigenous values used qualitative methods (15 of 21). Aspects of patient experiences categorised as being a characteristic for Indigenous values related overall to being able to receive information in their Indigenous language and the availability of a good translator, $^{16\ 25\ 59\ 67\ 69\ 71\ 94-99\ 112\ 113}$ health professionals and services being culturally responsive, $^{16\ 25\ 67\ 71\ 82\ 92\ 111}$ recognising traditional medicine or having a holistic perspective in care, $^{58\ 82\ 94\ 96\ 97\ 114}$ and when hospitalised, having access to traditional food, nature, social and cultural activities.

Patients in studies from Greenland and Canada stated issues with not being able to receive information in their Indigenous language in consultations, pamphlets or signs in the health centres.^{94 98 112 113} This was also linked with poor provision of good quality interpreters.^{25 59 69 98 99 111 113} In a Norwegian study, Sami patients felt that some medical terms did not exist in the Sami language, which challenged the patient–provider conversation.⁶⁷ Many studies conducted in areas with Sami populations reported Sami patients to have had negative experiences with healthcare providers not knowing and respecting their culture and customs^{59 67 69} enhancing existing mistrust from the colonial history.^{71 82}

Meaningful activities and access to traditional foods were important to patient experiences when hospitalised. A Norwegian study focussing on the benefits of providing traditional foods in dementia care, resulted in increased well-being and improved appetite among patients.⁶⁸ This was also experienced by Inuit patients in a Canadian study.⁹⁸ Three articles^{69 96 98} reported the healthpromoting benefits of time spent on the land. Of these, Hanssen⁶⁹ described how medical institutions often lack opportunities for Indigenous people to engage with the 'natural rhythm of life' through outdoor activities or consumption of traditional food.

Only three studies using qualitative or mixed methods mentioned climate change as an aspect influencing patients' experiences in healthcare.^{95 96 107} Bird *et al*⁹⁶ described how climate change was making it harder for Inuit living on Baffin Island to hunt country food and maintain their diabetes treatment plans.⁹⁶ Oosterveer and Young⁹⁵ and Wetterhall *et al*¹⁰⁷ noted how extreme weather conditions challenged patients' access to healthcare and transportation to hospital. These are aspects linked to climate change and circumpolar peoples' health experiences.

Studies with Inuit and Sami populations found that services were often too task-driven or medication-driven while lacking meaningful and patient-centred activities.⁵⁸ ⁶⁹ ⁹⁴ ¹¹⁴ Indigenous patients appreciated consultations where physicians listened instead of asking many questions.⁹⁷

Other patient experience aspects

Over half of all articles discussed the influence of health professionals' attitudes towards the patient as a determinant of patient satisfaction. Good professional skills were described in studies as: acting professional and making the patient feel relaxed or calm,^{86 93} close monitoring,^{32 35 87} professionals being confident and not seeming unsure in consultations,⁵³ competence of midwife as well as their presence without focussing only on their tasks created a safe haven.^{37 49}

Professionals' competence for compassionate care and ability to show empathy further influence patients experience of care.^{39 41 63 87 101 105} This was described in studies as nurses' and physicians' ability to resolve uncertainty,^{39 77 81} encouraging patients to ask questions and respecting patients' knowledge,^{29 42 87 103} meeting the patient's needs^{27 33 40 73} and being supportive.^{37 45 49 64 78} Negative patient experiences were rooted in poor support,^{33 48 79} indifference of staff towards patients or being ignored^{40 53 64 89 92} and personnel having a negative attitude.^{40 89}

Narratives from Norwegian community mental health centres pointed out an issue of power imbalance between male physicians and female patients.⁶⁶ Three studies found that patients did not feel comfortable to disagree or express criticism towards a health professional, or experienced that complaints were not properly recognised and handled.^{25 73 74 89}

Being respected as an individual and not only seen as a patient was associated with positive experiences,^{37 41 43 45 49 56 89 103 108 116} while the inverse, 'being referred to as a diagnosis rather than person',⁸⁹ was associated with negative experiences. Patients reported negative experiences when health personnel only read from the hospital record instead of listening to the patient⁸⁷ and were poor in communicating.^{43 60 94} Some studies' participants reported not having received sufficient information 26 30 $^{45-47}$ 52 58 64 73 79 79 93 96 97 113 118 leading to insecurity and vulnerability for some patients. 76 78 113 Consequently, gaining adequate and useful information was described to empower patients next to contribute to satisfaction. 28 213 210 40 43 50 54 65 77 80 83 87 105 113

Promptness¹⁰¹ and not being in a rush but having time when being with the patient was important for patient experience; this was also linked to complaints about short appointment times.^{31 37 40 56 87 89 94 111} In nine studies long waiting times for treatment and appointment, as well as diagnostic delay were reported and influenced satisfaction of care negatively.^{38 46 51 55 64 75 89 93 94}

Coordination of care and cooperation between professionals was also mentioned as adversely affecting the services patients received—the feeling of falling out of the system.^{45 46 64 87 93 106} In relation to this it was also important for patients to meet the same professionals in order to experience a greater continuity of care.^{34 45} Relatives' involvement in care and their support further contributes to a positive patient experience,^{36 47 80 84 94} since hospitalisation, for example, can lead to isolation and makes social support even more important.^{38 41 114}

Other aspects criticised by patients were the cleanliness, structure and quality of the facilities,²⁶⁷⁴¹⁰²¹¹⁵ lack of activities such as sports, parking spaces and heating systems,⁴⁰⁴¹⁸⁸ hospital food,⁴⁰ high costs such as medicines or even the lack of medicines.¹⁰¹¹¹⁵

DISCUSSION

This review aimed to scope the literature and identify peer-reviewed studies reporting on patient experiences of healthcare in the circumpolar region. We chose to use four predefined categories relevant to circumpolar health to provide structure to our results. These categories included rural and remote geography, telehealth, Indigenous values and climate change.

The most common descriptions of the rural and remote theme included patient experiences with travel costs, weather conditions influencing the ability to travel and lack of physicians influencing continuity of care. Increased accessibility of care and concerns about the ability to establish a personal relationship with providers were common descriptions relevant to the telehealth theme. Similarly, studies of Indigenous values in the experiences of healthcare included being able to speak one's own language during consultations, the difficulties of accessing an interpreter, access to traditional food and outdoor activities during hospitalisation, experiencing isolation from family and community when hospitalised and receiving holistic care.

This review demonstrates that rural and remote geography, telehealth, climate change and Indigenous values are highly relevant elements of circumpolar health systems. However, there are numerous other dimensions of care relevant to circumpolar populations that should be investigated further. One example is the relationship between

patient experiences and the environment. Climate change was a predefined category but only mentioned in 3 out of 96 articles. In a study that took place in Nunavut, diabetes patients described how changes in the climate have affected the migratory habits of animals which has impeded their ability to procure traditional foods. This has made it more difficult for these patients to obtain healthy food that can be used to manage their diabetes.⁹⁶ Other articles discussed how the increasing frequency of severe weather events has impacted patients travelling far distances to access treatment.^{95 107} Circumpolar literature has described the vulnerabilities of Indigenous and non-Indigenous peoples and the impacts of climate change on health and health systems. Impacts of climate change include changes in vectors of disease, emerging epidemics, food security, increases in land-based injury and mental health issues.^{119–123} Considering the myriad effects of climate change on the health of northern populations, in particular Indigenous groups who depend on natural resources for their well-being,¹²⁴ the natural environment could be explored as a critical determinant of patient experiences for circumpolar populations.

Contextualising climate change as a determinant of patient experiences would necessitate a broader definition of what constitutes a 'health system'. This shift away from the framework that defines health systems as the sum of institutions and resources that deliver health services to a population requires a values-based conception grounded in the circumpolar context and especially in Indigenous knowledge.^{125,126} A multinational group previously identified and described nine values essential to integrating Indigenous ideologies into health system stewardship.¹ Many of these values, such as cultural responsiveness, kinship and holism were echoed in much of the Indigenous literature included in this review. An expanded definition of health systems that not only takes into account the experiences of patients within healthcare facilities, but also of individuals enhancing their mental and physical health through on-the-land activities, would be more concordant with the circumpolar context. Additionally, it would enable capture of relevant information that could guide health system improvement, such as features in the community and natural environment that promote health. A panel of circumpolar health experts previously noted that moving away from the "narrow paradigm of 'health systems'" would be necessary to promote systemwide changes that support patients.¹²⁵

Another critical component of making health systems more responsive to patient experiences is evaluation. Some regions rely on survey-based methodologies to collect patient feedback, while others use interviews, focus groups and other qualitative methodologies. In this study, we found that Scandinavia accounts for the majority of the quantitative studies, where patient satisfaction is often rated from predefined questionnaires. This is a method used to standardise evaluation of both patients' views on facilities, information and elements of treatment and to optimise and improve these areas. Qualitative studies are used to access a more nuanced knowledge of perceived satisfaction and experience of the individual or smaller groups. Qualitative methods were more frequently employed in studies originating in Canada, Alaska and Greenland. Notably, these were the same countries that reported most on Indigenous values and rural/remote themes. Additionally, climate change only came up as a factor in qualitative and mixed-method studies, which emphasises the importance of using qualitative methods to gather data on what is truly important to patients rather than solely relying on standardised surveys.

This discussion of aligning health systems more closely with patient needs benefits from a review of global literature from settings that share similar characteristics with circumpolar regions. Australia, which also has large rural and remote areas as well as an Indigenous population, has framed these discussions around patient experiences through the lens of cultural safety and has developed a monitoring framework that measures the cultural responsiveness and experiences of patients within the health system.¹²⁷ Cultural safety is also emerging as a priority for circumpolar national and Indigenous governments and this framing of patient experiences warrants further consideration for circumpolar nations where colonial legacies are prominent in health services. Numerous studies of Aboriginal and Torres Strait Islander populations identified themes that this study also found to be relevant to circumpolar Indigenous groups, including traditional foods, language services, coordination of care and the importance of Indigenous staff members.¹²⁸ 129 These similarities suggest that changes meant to improve the experiences of patients within circumpolar health systems could be grounded by previous successes found elsewhere in the world.

This scoping review is both comprehensive and thorough; no restrictions limited the search by language or date of publication. This allowed for the broadest inclusion of relevant articles possible. Since 96 relevant articles were included in our review, we chose not to search for grey literature. We abstained from applying an external framework; this allowed for an analysis grounded more organically in the data provided and responsive to the circumpolar context.

Furthermore, nearly every article identified through the search criteria could be accessed in full text, and all full texts were reviewed by multiple authors. Similar redundancy was built into the data extraction process. These procedures ensured accuracy and rigour.

Based on this extensive review, next steps could involve the development of a circumpolar patient experience framework to guide future studies and comparative work in this area. Furthermore, a review of the existing grey literature would also be relevant, since, to our knowledge, not all research conducted in the circumpolar region is published in peer-reviewed journals. Additionally, this work could be further contextualised in sharing circles and other community-based participatory methodologies to enable validation of themes and additional comparison. Such approaches would enable future studies and health systems to become more responsive to the needs of circumpolar populations.

Correction notice The article has been corrected since it is published. The previous table 2 format has been updated as Figure 5.

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