

“It’s Trust. That’s Everything”: Care providers’ experiences supporting Inuit participation across the Qikiqtani–Ottawa care journey

Janet Jull

janet.jull@carleton.ca

Carleton University

Kimberly Fairman

University of Victoria

Katy Pollack

Carleton University

Pål Gulbrandsen

University of Oslo

Felicia Adelaja

Tungasuvvingat Inuit

Parniga Akeeagok

Government of Nunavut

Aimo Akulukjuk

Government of Nunavut

Juan Francisco Bermúdez

Tungasuvvingat Inuit

Diego Cezer

The Ottawa Hospital

Michelle Day

The Ottawa Hospital

Mackenzie Daybutch

The Ottawa Hospital

Ida Davidee

Carry-Anne Dolan

Larga Baffin

Treene Greene

The Ottawa Hospital

Brittany Hesmer

Carleton University

Louisa Kipsigak

Government of Nunavut

Theresa Koonoo

Government of Nunavut

Carly Little

Tungasuvvingat Inuit

Susie Onalik

Government of Nunavut

Rosie Simonee

Tungasuvvingat Inuit

Akumalik Tikivik

Tungasuvvingat Inuit

Jemimah Thomas

Tungasuvvingat Inuit

Meeka Uniuqsaraq

Malaya Zehr

Larga Baffin

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Abstract

Background: Canada's health and social care system serves people in Inuit Nunangat within a context influenced by history, geography, and care organization. These conditions create challenges for Inuit communities and providers. Shared decision making is an approach to person-centred care in which care providers and care recipients make decisions together and support autonomy and participation across the care journey. This study examined care providers' experiences supporting Inuit travelling from the Qikiqtani region of Nunavut to Ottawa, Ontario, and factors influencing their ability to support participation in care decisions.

Methods: The Not Deciding Alone team is a partnership of Inuit-led and service organizations, community partners, and academic researchers across Ontario and Nunavut. We conducted an interpretive descriptive qualitative study using interviews with care providers supporting Inuit in Ottawa and/or the Qikiqtani region. We examined how providers support care recipients across the care journey and what influences participation in decision making. A framework developed with Indigenous and Inuit partners guided the study and depicts participation as highly relational. The Inuit societal value of *aajiqatigiingniq* informed the approach and supported research co-production. Inuit knowledge and shared governance were centred, with team members engaged as partners from developing research questions through interpreting and applying findings.

Results: Fourteen care providers participated, with roles spanning the care journey from community to urban settings. We identified four themes: 1) actively supporting navigation within complex and fragmented systems; 2) fostering collaborative relationships within challenging care settings; 3) creating conditions for participation; and 4) relational care and trust as essential to Inuit participation. Across themes, providers showed strengths in supporting communication, continuity, navigation, and engagement, while describing system conditions that limited what they could offer.

Conclusions: Inuit participation in care decisions depends on the conditions people encounter when entering care systems and on how care is organized and delivered. Care providers work within systems that can limit their ability to support participation. Shared decision making can help put person-centred care into practice. We propose understanding shared decision making as a relational practice and a systems-level lens for identifying conditions that enable or constrain care providers and care recipients to make decisions together.

1. Background

Delivery of Canada's publicly funded health and social care system to people living in Inuit Nunangat (the Inuit homeland) occurs within a layered context of history, geography, and care organization, with impacts on care decision making (1, 2). These contexts and their intersecting factors influence care access experience, and uptake. People living in Nunavut must often travel to southern regions of Canada to access care services (3). Medical travel and the related challenges of accessing and using care are significant concerns for Inuit community members and care providers (2, 4–6).

Historically, interactions with care systems have been impacted by colonial policies and practices, including medical evacuation, separation from family for treatment, and centralized decision-making processes (3, 7). Care systems' access for Inuit, and other Indigenous groups in Canada, is complicated by negative health care experiences (3, 8, 9). These experiences have contributed to institutional mistrust and have limited opportunities for Inuit to direct decisions affecting their health and wellness.

Geographic realities further frame care experiences. Many communities are remote and fly-in only, with access to care dependent on weather conditions and transportation availability. In communities, primary care is typically delivered through nursing stations, with additional services often requiring travel to regional or southern centres (6, 10). Care may involve nursing stations in the North and hospitals in southern centres, with rotating physicians, locum care providers, and interdisciplinary teams providing service delivery (11). This context structures how and when care recipients engage with care providers, affecting opportunities for participation in decision making about care.

This study focuses on Inuit, the Indigenous Peoples of Inuit Nunangat, the Inuit homeland in Canada (12), and builds upon previous research by the Not Deciding Alone team: a partnership of Inuit-led and service organizations, community partners, and academic researchers across Ontario and Nunavut. As members of this team, we seek to strengthen participation in care through shared decision making. Earlier research by the Not Deciding Alone team identified points along the care journey where Inuit travelling from Nunavut to urban settings experienced limited opportunities to participate in decisions, and where care providers may determine these experiences through a "decision chain" (5).

Person centred care and shared decision making

In Canada, Indigenous Peoples include First Nations, Inuit, and Métis; distinct groups with unique histories, languages, cultural practices and spiritual beliefs (13). Across these groups, structural and systemic barriers continue to contribute to inequities in access to care, care experiences, and opportunities to participate in care compared with non-Indigenous populations (14, 15). There is a need to address societal imbalances of power, and support opportunities for health and wellness of Indigenous Peoples. Addressing these barriers requires approaches that support self-determination and participation, consistent with the United Declaration on Rights of Indigenous Peoples (16) and the Calls to Action of the Truth and Reconciliation Commission of Canada (7). Within this context, care providers influence care recipient autonomy and capacity to participate in care (17).

Person-centred care involves recognizing individuals and families as partners in care systems, bringing their values and perspectives to decisions about their health (18). Care is understood as a collaborative and active process between individuals and care providers. While this approach is associated with improved quality of care, well-being, and safety (19, 20), it is not consistently realized in practice. Despite commitments to person-centred care in health policy, clinical guidelines, and health system priorities (21–23), many individuals lack opportunities to participate in care decisions (24, 25).

A foundational approach to person-centred care is shared decision making, a process in which care providers and care recipients make decisions together about tests, treatments, and health management, informed by care recipients' values and preferences (26, 27). Building on this definition, we understand shared decision making as an ongoing relational process through which care providers support autonomy and participation across the care journey (17, 26). We use the term "care providers" to include those who are engaged in actions whose primary intent is to protect and improve health (28), and "care recipients" to include those seeking care and to reflect a person-centred and relational perspective. While shared decision making has been identified as particularly beneficial for populations who experience inequities (29), its application is influenced by broader structural and relational contexts that impact its use in practice (30).

In this paper, we examine care providers' influence across the care journey by: 1) exploring their experiences supporting Inuit traveling from the Qikiqtani region of Nunavut to Ottawa, Ontario for care; and 2) identifying the factors that influence their ability to support Inuit care recipients' participation in care decisions.

2. Methods

Design and Theoretical Orientation

We conducted an interpretive descriptive qualitative study using individual interviews with care providers. Building on our previous work mapping the care journey from the perspective of Inuit care recipients (5), we sought to understand the experiences of the care providers who support that journey, including the factors that influence their ability to facilitate participation in care decision making. Interpretive description was developed for applied health research and is well suited to understanding clinical and care-related experiences (31). In this study, it supported an iterative relationship between data collection and analysis, informed questioning during interviews, and ongoing researcher reflection. This process enabled the development of an interpretive account of care providers' experiences and the conditions influencing their ability to support Inuit participation in decision making.

We used a framework developed by Indigenous and Inuit partners to guide our understanding of participation in care and decision-making as highly relational. The Shared Decision Making Process framework was developed in collaboration with Inuit partners to organize key concepts related to Indigenous perspectives and shared decision making, drawing on both Indigenous and non-Indigenous frameworks and models (30). It describes participation in decision making affected by context and the people involved and was used to develop the interview guide and support interpretation of findings.

Collaborative Research Approach

Our team prioritized Inuit approaches to build consensus and address Inuit-specific health issues, to ensure meaningful engagement, mutual respect, learning, and reconciliation (32–34). The Inuit societal value of *aajiiqatigiingniq* involves collective and iterative processes for building consensus and seeking solutions, and guided our team's actions (33, 35). It is central to Inuit notions of wellness and community harmony (36). This value informed our research approach and supported research co-production.

We structured the study to centre Inuit knowledge and ensure shared governance, engaging team members as full partners throughout the research process, from defining research questions to the application of findings (37). In research co-production all team members bring their expertise to the knowledge production process, and the outputs of the research are more likely to be useful, usable and used (38). Research co-production supports the coexistence of multiple knowledges within academic and care systems (39, 40). Consistent with *aajiiqatigiingniq*, the team co-led the study conceptualization, design, conduct, and dissemination with researchers (JJ, KF, KP), using our previously developed collaborative approach to community-academic research partnerships (41). This study is situated within a broader program of research focused on supporting shared decision making with Inuit care recipients.

Not Deciding Alone Team and Reflexivity

The team brought experience in Inuit societal values, Indigenous health, person-centred care, shared decision making, collaborative research and co-production, knowledge mobilization, and qualitative methods. The first author (JJ) identifies as a woman of Euro-Canadian descent and is a care provider and academic researcher who has expertise in mixed methods research, including qualitative methods. KF identifies as a woman of Inuit descent and is a program administrator and researcher experienced in community led and Inuit researcher methods. KP identifies as a woman of Euro-Canadian descent and is a policy analyst and academic researcher experienced in mixed methods research.

The team shares a commitment to improving Inuit access to and experiences of care and is developing and field-testing shared decision making education for care providers working with Inuit. We understand accessibility as a systemic, justice-based practice informed by relational accountability, intersectionality, and collaborative practices (42, 43). This orientation directed the team's attention to the structural and systems level conditions that affect peoples' opportunities for participation in care. Throughout the study, the research team used reflexive dialogue during meetings to examine how our positionalities, professional roles, assumptions, and relationships with Inuit communities could influence the study design, data collection, analysis, and interpretation. These discussions supported critical consideration of power, relationships, and the limits of our perspectives throughout the research process (e.g., see 44,45). This study builds on earlier research in which Inuit community member perspectives on health care experiences and impacts on care decision making informed the broader program of shared decision making research (5).

Participants and procedures

Participants were care providers who provided care to Inuit community members in Ottawa, Ontario and/or the Qikiqtani region of Nunavut. We recruited participants from interdisciplinary backgrounds across care services, including direct care providers and others who support Inuit throughout the care system. Participants were 18 years and older and able to participate in an interview in English. We anticipated that 10–13 participants would provide sufficient depth and diversity of perspective and selected individual interviews to support dialogue with care providers about: 1) their experiences supporting Inuit travelling from the Qikiqtani region of Nunavut to Ottawa, Ontario, for care; and (2) the factors that influence their ability to support Inuit care recipients' participation in care decisions.

Participants were recruited through purposive and network-based stratified sampling strategies (46) by sharing the study poster by email through team networks and sharing printed copies in public places (bulletin boards) at partner organizations. Sampling was informed by the range of care provider roles identified in our previous journey mapping study, with the aim of including perspectives from across the care journey. Some participants may have been known to members of the research team before the study. Recruitment occurred through sharing the study information (poster) within these networks and interested individuals self-identified and contacted the research team member (JJ). Due to the use of network-based recruitment and the sensitivity of the topic within a relatively small provider community, the number of individuals who received the study invitation was not tracked. All individuals who expressed interest were enrolled in the study. Given the close-knit nature of these provider networks, particular attention was paid to ensuring voluntary participation and maintaining participant confidentiality and anonymity throughout the study.

We invited and informed care providers about joining the study in accordance with community and institutional protocols and research ethics requirements. Interviews were conducted in English in settings convenient to participants, including virtual or in-person formats.

After reviewing and signing the consent form, participants were interviewed for 40 to 60 minutes using semi-structured interviews. The interviews included a request for non-identifying demographic information. Participants were not required to answer any questions they did not wish to answer. Interviews were digitally recorded, transcribed verbatim, and researcher field notes were included with the data.

Participants were offered the opportunity to review their transcripts as part of member checking. Two participants made changes by adding information to their transcripts. Interviews were conducted by JJ, and no one else was present during the interviews. The interviews were analyzed by JJ, KF, and KP, researchers trained in qualitative research. The team, who include co-authors on this paper, brought their experience in working with Inuit communities and care providers to reflect on the synthesized findings generated from the interviews.

Data collection

An interview guide was developed based on the Shared Decision Making Process Framework (30) and in collaboration with the research team. It included open-ended questions and prompts exploring care providers' experiences supporting Inuit who travel from the Qikiqtani region of Nunavut to Ottawa for care. Questions also examined the factors that influence providers' ability to support Inuit care recipients' participation in decisions with members of their care team. The guide was pilot tested and refined with the research team before data collection.

Data analysis

Demographic data were entered into an Excel database for descriptive analysis. Qualitative software (47) was used to assist with data analysis. Transcribed interviews were analyzed using a six-phase process of thematic analysis within an interpretive descriptive approach (48). In this iterative analysis, JJ led the initial and primary coding processes. Subsequently, KP and KF conducted secondary coding to verify categories and refine themes. The full team held three online and one in-person meeting to discuss interpretive differences, discrepancies, and collaboratively agree on the study findings. The team considered the sufficiency of the data (49) throughout analysis and to determine that additional interviews would not contribute substantially new insights relevant to the study aims.

Reflexivity was central to the analysis as team member social and professional locations influence qualitative interpretation (50, 51). Due to the colonial histories in research (52), ongoing dialogue between team members enabled critical examination of how power, positionality, and assumptions about autonomy and shared decision making influenced data interpretation and representation. Findings were finalized through team discussion and reflection. This approach supported the identification of understandings of the factors that influence care providers' ability to support Inuit participation in decisions about care.

Ethics

The approach to this study was informed by the Truth and Reconciliation Commission Report (7) and the inquiry on Missing and Murdered Indigenous Women and Girls (53). Our research approach reflects the team focus on conducting research in collaboration with Inuit and those they identify as partners in care.

Our study aligns with the National Inuit Strategy on Research (NISR), which upholds Inuit self-determination in research (12). The study was informed by Inuit Qaujimajatuqangit (IQ) guiding principles, which are Inuit societal values that promote self-determination, self-reliance, collaboration, and knowledge development that is appropriate and beneficial for Inuit (54, 55). Study partnerships were structured through a mutually agreed-upon ethical framework intended to uphold community values and ethical practices (56). This framework included the IQ guiding principles (54, 55), the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (TCPS 2) including Chap. 9 on research involving First Nations, Inuit and Métis Peoples (57), and the CIHR Guidelines for Health Research Involving Aboriginal People (2007–2010) (58, 59).

Ethics approval

for this study was obtained from the Carleton University Research Ethics Board (#121757), in accordance with the TCPS 2 including Chap. 9 on research involving First Nations, Inuit and Métis Peoples (57). The study was licensed by the Nunavut Research Institute (#02 045 23N-M) and underwent local community review with Ittaq Heritage and Research Centre. All participants provided written informed consent prior to participation. Measures to protect confidentiality included de-identification of interview data, secure data storage, and attention to the potential for indirect identification within a small provider community. This study is reported with the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist (60) and the Consolidated criteria for strengthening reporting of health research involving Indigenous Peoples (CONSIDER statement) (61).

3. Results

Fourteen interviews were conducted with care providers in a range of roles across the care journey, from community to urban settings. We exceeded our initial projected maximum number of 13 interviews due to strong community interest, with no drop outs. Participants varied in age from their 30s to their 60s, had worked in their current roles for between 2 and more than 30 years, and the majority self-identified as women. Their experience supporting Inuit ranged from seeing a small number of Inuit travelling for care each week, to spending most of their working time supporting Inuit in their care journeys. Participant characteristics are reported in aggregate, and quotations are not attributed by participant number or professional role to protect anonymity within the relatively small and interconnected network of care providers. Unique codes ranging from P01 to P14 were assigned and the chronological order of the interviews was randomized during the code assignment (JJ to do).

We identified four themes, with the first three describing how care providers actively support Inuit to participate in care systems. These themes highlight provider strengths and the factors that influence their ability to support Inuit care recipients' participation in care decisions.

1. Actively supporting navigation within complex and fragmented care systems: "The system means people don't get information"
2. Fostering collaborative relationships within challenging care settings: "I'm gonna keep checking in with you"
3. Creating conditions for participation: "...Care providers are afraid of silence. Inuit are not afraid of silence"

A fourth, foundational theme was identified to explain how participants described highly relational care and trust as fundamental to Inuit participation: "...It's trust. Yeah, that's everything."

Theme 1: Actively supporting navigation within complex and fragmented care systems: "The system means people don't get information."

Participants described actively supporting care recipients to navigate and make choices within complex care systems that are often cross-jurisdictional. The delivery of services is influenced by geography and care system infrastructure that impact how and where care is delivered. Participants explained how individuals frequently travel long distances for specialized and emergency care that cannot be provided in community settings: "The [care providers] based in the North can do basic procedures, but they're not specialists." [P02] Participants also described multiple pathways into the care system, including emergency transportation and scheduled travel: "Well, there are a couple of different ways where they are sent down from the north... they'll be Medevac'd down¹... and there are other types [of medical travel] where they would be picked up at the conventional airline." [P06] These entry points may require individuals to navigate complicated and unfamiliar medical travel systems while managing complex health concerns, often with limited information as stated by one participant: "The system means people don't get information." [P07] These conditions reflect the challenges in access to and coordination of care.

Participants described taking an active role to help care recipients navigate these conditions, often working with incomplete or delayed information. They emphasized that care recipients frequently experience uncertainty and isolation when traveling for care: "...The rush of travelling to Ottawa, maybe without an escort... A lack of family support... Worrying about what's going on at home." [P09] These experiences occur in cross-jurisdictional systems, that differ in their resources and infrastructure: "They're coming into a completely different health system... including use of email and electronic health records, and I think that's got to be tricky too." [P05] This situation can create uncertainty and complicate continuity of care as individuals move between care systems.

Formal supports such as medical travel, accommodation, and escort roles² were described as essential in facilitating navigation: "There are many organizations working to help people in the care system... to help people navigate the system." [P10] The role of escorts was particularly emphasized: "The medical escort is not somebody that's coming down here just for a fun time, but to support the recipients of care." [P01] Participants emphasized that care recipients may delay or refuse care without this support: "I just remember having a patient... they didn't want to go unless they have a specific family member escort them." [P07] However, these supports were also described as insufficient and as compensating for broader systemic gaps that leave people unsupported.

Within these conditions, participants described how important it is that they work to bridge the gaps: "If the person does not have the support of the health care providers... it's like they need to have some support to have their say." [P06] Participants described care providers as seeing the challenges of the system and the importance of support for Inuit participation in care.

Theme 2: Fostering collaborative relationships within challenging care settings: "I'm gonna keep checking in with you."

Participants emphasized the importance of building and maintaining collaborative relationships with care recipients and their families. Within care encounters, they described engaging in ongoing communication, described by one participant "...I'm gonna keep checking in with you." [P07] Participants described their role as actively supporting care recipient understanding and mediating information within the system: "I can't stress enough about

services providing information and what things mean. And you don't do it one time. You do it on a regular basis." [P03] These efforts reflect an ongoing commitment to collaborative relationships.

Participants described conditions that impact collaboration. Role assignments and workload were identified as limiting their opportunities for consistent engagement with care recipients: "I think everyone is assigned a role, but because of volumes, they seem to only kind of step in when they're needed." [P07] They also described limited coordination across teams: "We do not know what the health care provider networks do... We are uncoordinated." [P05] These accounts highlight how organizational structures may limit their collaboration.

Within these constraints, participants described taking initiative to support collaboration. Some described informal roles, where individuals advocate within teams and share knowledge to support care for Inuit patients: "They really stepped up... and became champions with the team." [P03] The participants described the roles as helping to address gaps in coordination and understanding and noted that such efforts often rely on individual initiative. Some participants identified the formal role of system navigators in facilitating coordination across systems: "The navigators have tremendous relevance, not just for the navigator and recipients of care, but for the whole system. The best situation would be that navigators are well supported and able to do their job." [P11]. However, most providers did not report on the navigator role as available to support care recipient and provider relationships within the system. Overall, participants described collaborative care as highly valued and influenced by conditions that require care providers to take initiative to support participation in care.

Theme 3: Creating conditions for participation: "...care providers, they are afraid of silence. Inuit are not afraid of silence."

Participants described how the way care was organized and delivered could either create or restrict opportunities for Inuit care recipients to participate. Care system processes were reported to be often inflexible and to limit personal agency. For example, medical travel could be arranged with little notice and no choice: "This is a date you're coming and that's it. You're getting on the plane on this day and this time. And sometimes those notices can be very short, from what I've heard." [P12]

Appointment structures also reflected expectations about how care interactions should proceed. Participants described how pressure to move quickly could leave little opportunity for silence, reflection, or meaningful engagement: "The one thing that appointments lack right now is a moment of silence. People who are care providers; they are afraid of silence. Inuit are not afraid of silence." [P04] These examples illustrate how organization and communication norms of care can privilege particular ways of participating. Limited flexibility and time can reduce opportunities for care recipients to express their views and contribute to discussions.

Within these conditions, providers described adapting their practices to create opportunities for participation. This included allowing more time and following the care recipient's priorities: "...you have to follow their agenda. What is their priority? You have to be flexible." [P05] In summary, participants described participation as dependent on the conditions under which care occurs and the ways providers respond within those conditions.

Foundational Theme: Building trust through supportive, relational care "...It's trust. Yeah, that's everything."

Across all interviews, participants described trust and supportive, relational care as foundational to care experiences. Trust was described as central to relationships with care recipients and as essential to supporting engagement and participation in care: "So it's really, it's trust. Yeah, that's everything." [P01]

Participants emphasized the importance of understanding care recipients' contexts, including their communities and lived experiences of their health issues. As most care providers do not come from the same area as recipients traveling from the north, it can be difficult to understand the perspective of people when they arrive for care: "As a provider, we need to know the context of what Nunavut looks like and where they live in their community. To make a decision with the patient, sometimes you need to know." [P05] Developing this understanding was described as requiring ongoing learning and openness. Limited access to training and resources was identified as a barrier: "The provider has to do their own training to know what it is we can do." [P13] Participants also emphasized the importance of self-awareness, including recognizing how communication styles and assumptions influence their interactions: "We can teach people, health care providers, active listening, but unconscious bias and personal baggage will impact their interactions." [P11] One participant spoke about how care providers could build their skills and knowledge to offer proactive support: "Instead of waiting for a patient to ask for a culturally supportive thing, why don't you, the health care provider, offer it? Don't wait and then say, oh well, let me look into that and see what I can find." [P14]

Participants explained that education in supportive care could help care providers offer services within systems that may not feel safe to care recipients from the North, given troubling historical and ongoing realities. They described how historical trauma can impact how support is received and noted that standard practices in care systems, that may be viewed as helpful for some recipients, could feel intrusive for others: "You know, it's not easy when you think about historical trauma. It's easy to say, I think you should see a social worker. For some people, it's like, you know, I don't need more people prying into my life. I'm already uprooted. I'm already here." [P01]

Some participants also emphasized the importance of cultural interpretation and the challenges associated with limited access to interpreters: "And, a really good assessment of whether the individual needs a cultural interpreter at the point of interaction with health care providers and teams... sometimes I think there's an assumption that they are young, they're from [place], they should be just fine. There is a need to differentiate between linguistic and cultural interpretation." [P08] They also explained the implications of limited access to these supports and the burden on interpreters: "If you don't luck out and get an interpreter, then you're really on your own. Pretty much. That's a big burden on the interpreter. Everybody wants them." [P13] Overall, participants described trust as foundational to care experiences and to how care is enacted across all aspects of the system.

Across themes, participation in care was influenced by multiple interacting factors. Providers' accounts showed how the organization of care and relationships between providers and care recipients could both support and constrain participation.

4. Discussion

This study examined care providers' experiences supporting Inuit travelling from the Qikiqtani region of Nunavut to Ottawa, Ontario, for care, with particular attention to the factors that influence their ability to support Inuit care recipients' participation in decisions throughout the care journey. Inuit care recipients often begin this journey already facing substantial barriers to participation. Travel, separation from family and support networks, unfamiliar services, and limited access to information can reduce opportunities to prepare for and participate in decisions about care (5). These challenges reflect broader issues of accessibility, including how health services are organized and distributed and how people move through care systems (1, 64). They are structured by wider social and historical conditions, that include the ongoing impacts of colonialism (64).

A previously developed journey map, based on the experiences of Inuit travelling from the Qikiqtani region to Ottawa for care, described the barriers and facilitators influencing participation in decision making from the perspective of care recipients (5). Our study complements and extends this work by examining the perspectives of some of the care providers who are engaged across these care journeys. In doing so, it demonstrates that care providers work within structural conditions that constrain their ability to support care recipients' participation in decision making, even as they seek ways to respond to or work around these constraints. Reflecting on these experiences through the lens of participation in care decision making helped identify the factors influencing care experiences. Furthermore, it can support identification of opportunities for care providers to advocate for changes to the structures that underpin care systems.

(Fig. 1. Health care providers across the care journey)

Power within constrained systems

Care providers described working within fragmented systems to provide support to care recipients traveling from the Qikiqtani region. Although providers hold interpersonal power within care relationships (65, 66), their capacity to support participation is limited by structural conditions that often determine what information, options, and supports are available before a clinical interaction begins. Providers responded by helping care recipients navigate services, maintaining communication, and adapting their practice to create conditions for participation. These efforts often relied on providers informally compensating for gaps in the provision of care.

These findings are consistent with research showing that care providers exercise discretion in their day-to-day work while remaining constrained by wider systems and institutional arrangements (67, 68). They also align with literature emphasizing the importance of reflective and flexible practice in responding to inequities in care (69). Providers in our study further emphasized that trust, culturally responsive communication, and adequate system-level support are necessary to allow them to do the work to meet the needs of care recipients, a point also supported in the literature (67, 70).

Participation develops across the care journey, and providers exercise interpersonal power through the opportunities they create for care recipients to engage in decisions. At the same time, structural constraints limit what providers can offer. This tension helps explain why shared decision making may remain restricted even when providers intend to support participation and care recipients want to contribute meaningfully, a concern also identified by Joseph-Williams et al. (71). Roher et al. (72) describe how colonial structures affect authority, trust, access to care, and the recognition of Inuit knowledge within health care. Our findings provide concrete examples of how these structures can become visible in everyday care practices and influence both Inuit care recipients' opportunities to participate and care providers' ability to support that participation.

Shared decision making as a system-level approach to person-centred care

Shared decision making operationalizes person-centred care by supporting collaboration between care providers and care recipients. Although it is often implemented through training focused on individual communication skills, these practices can be difficult to sustain in routine care. Interventions to support shared decision making can be effective (73), yet they remain underused because decision making is context dependent and implementation is often hindered by conditions within routine care (74, 75). Care system conditions, including time constraints, workflow, and service organization, can limit implementation and opportunities for care recipients to participate in decisions about their care (76–79). These barriers can persist despite provider training and other educational initiatives (80). Our findings similarly suggest that focusing on individual practice places responsibility on providers and care recipients while leaving the conditions that constrain participation in decision making about care unaddressed.

Shared decision making has been described as a method of care that is as fundamental to clinical practice as assessment, diagnosis, and treatment (81). Our findings suggest that shared decision making can also provide a useful lens for examining the systems in which care occurs. A system-level perspective draws attention to how the organization, coordination, and resourcing of care enables or constrains opportunities for participation (82). Understanding shared decision making as both a relational practice and a system-level lens encourages reflection on how decisions are made and on the conditions under which they occur. Supporting providers to engage in collaborative decision making must therefore include addressing barriers related to access, coordination, and continuity of care (83). This broader perspective is consistent with evidence that participation depends on organizational culture, relationships, resources, communication, and power (84). Our findings suggest that shared decision making can be applied to identify the conditions that influence participation in care and inform efforts to address them.

Limitations

This study reflects care providers' perspectives and does not include the views of Inuit care recipients. The findings should therefore be interpreted alongside prior and ongoing work within this program of research that centres Inuit perspectives. Participants were recruited through purposive and network-based sampling within a small, interconnected provider network, which may have favoured individuals with similar experiences or commitments to supporting participation. The study was also conducted within specific care contexts in Ottawa and the Qikiqtani region, and findings may not transfer to regions with different services, resources, or care pathways. Future studies should bring together Inuit care recipients, families, providers, and system partners to examine participation across diverse care journeys and evaluate strategies that address the relational, organizational, and structural barriers identified here.

5. Conclusion

This study shows that Inuit participation in care depends on the conditions people face when they enter care systems and on how care is organized and delivered. Many Inuit care recipients encounter substantial barriers as they move through the care journey. Care providers also work within systems that can limit their ability to consistently support care recipients' participation in decisions about their care. Our findings illustrate how commitments to person-centred care in policy and health system priorities may not be realized in everyday care delivery. Shared decision making can help operationalize person-centred care, although its impact is limited when it is treated as an individual communication practice. We propose understanding shared decision making as a relational practice and a systems-level lens for identifying the conditions that enable or constrain care providers and care recipients to make decisions together, and for informing efforts to strengthen participation in care.

Abbreviations

Not applicable

Declarations

Ethics approval and consent to participate

Ethics approval for this study was obtained from the Carleton University Research Ethics Board (#121757) in accordance with the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (TCPS 2), including Chapter 9 on research involving First Nations, Inuit and Métis Peoples (57). The study was licensed by the Nunavut Research Institute (#02 045 23N-M) and underwent local community review with Ittaq Heritage and Research Centre. All participants provided written informed consent prior to participation. Measures to protect confidentiality included de-identification of interview data, secure data storage, and attention to the potential for indirect identification within a small provider community.

Consent for publication

Not applicable

Availability of data and materials

Data are available from the authors upon reasonable request.

Competing interests

The authors declare that they have no competing interests.

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Authors' contributions

Janet Jull: conceptualization, methodology, investigation, formal analysis, writing - original draft, writing - review & editing, supervision, project administration, funding acquisition

Kimberly Fairman: conceptualization, methodology, formal analysis, validation, writing - review & editing

Katy Pollack: formal analysis, validation, writing - review & editing

Pål Gulbrandsen: conceptualization, methodology, validation, writing - review & editing

Felicia Adelaja: methodology, validation, writing - review & editing

Parniga Akeeagok: conceptualization, methodology, validation, writing - review & editing

Aimo Akulukjuk: conceptualization, methodology, validation, writing - review & editing

Juan Bermudez: methodology, validation, writing - review & editing

Diego Cezer: methodology, validation, writing - review & editing

Michelle Day: methodology, validation, writing - review & editing

Mackenzie Daybutch: conceptualization, methodology, validation, writing - review & editing

Ida Davidee: conceptualization, methodology, writing - review & editing

Carry-Anne Dolan: validation, writing - review & editing

Treena Greene : conceptualization, methodology, validation, writing - review & editing

Brittany Hesmer: conceptualization, methodology, validation, project administration, writing - review & editing

Louisa Kipsigak: conceptualization, methodology, validation, writing - review & editing

Theresa Koonoo: conceptualization, methodology, validation, writing - review & editing

Carly Little: methodology, validation, writing - review & editing

Susie Onalik: conceptualization, methodology, validation, writing - review & editing

Rosie Simonee: methodology, validation, writing - review & editing

Akumalik Tikivik: methodology, validation, writing - review & editing

Jemimah Thomas: methodology, validation, writing - review & editing

Meeka Uniuqsaraq: methodology, validation, writing - review & editing

Malaya Zehr: conceptualization, methodology, validation, writing - review & editing

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Footnotes

1. Medical evacuations or ‘medevac’ flights are Nunavut’s emergency air ambulance service that fly care recipients from their home communities to the nearest hospital. They are used when there is an immediate and urgent care need (62)
2. The medical escort role is recommended by a care provider and approved by government essential care partners for people who require assistance during medical travel. They provide support during the care journey and stay with the person receiving care at all reasonable times (63)

Figures

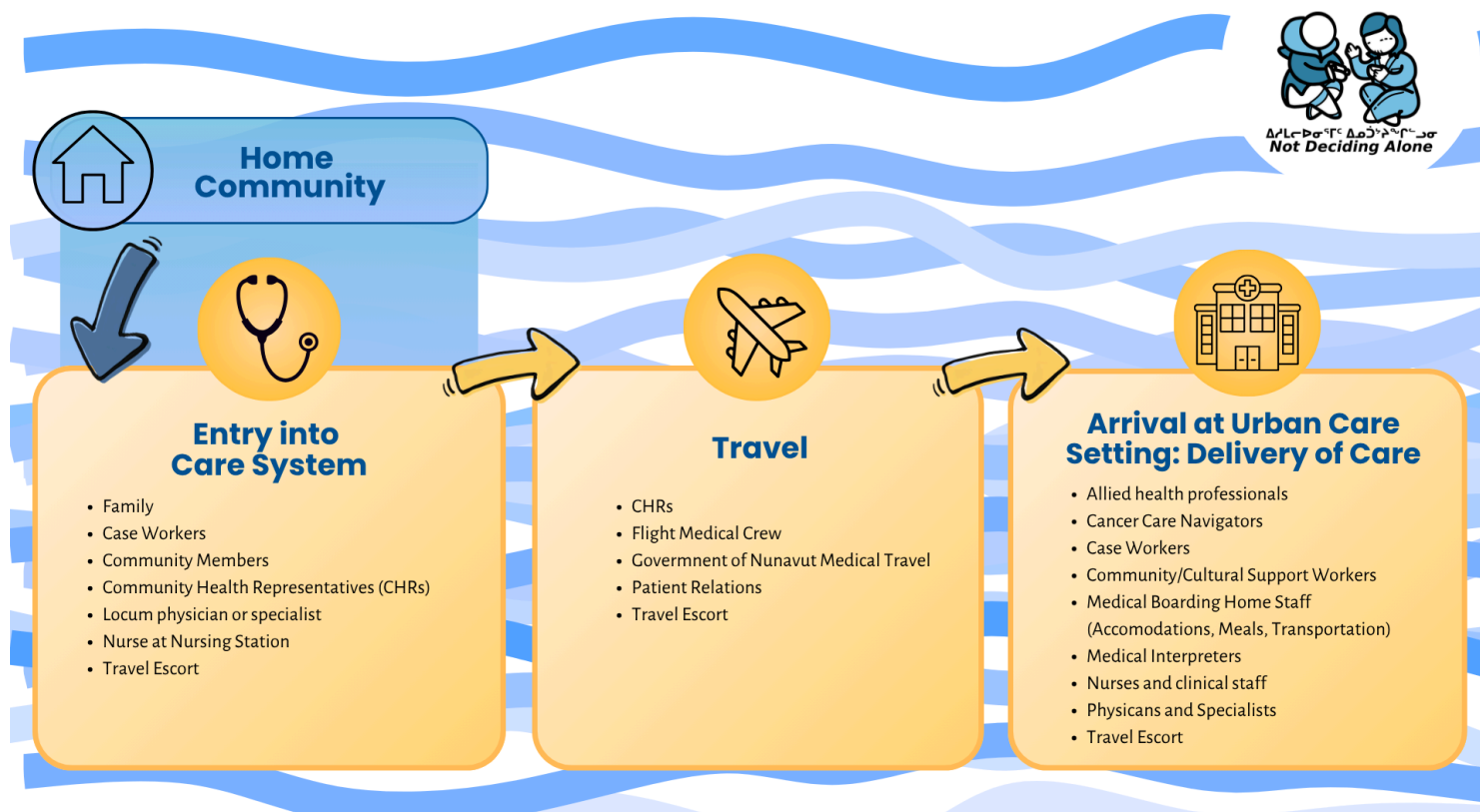


Figure 1

Health care providers across the care journey

Supplementary Files

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- [File1.Interviewquestionstoexplorethejourneyanddecisionmaking.docx](#)