

Provision of comprehensive, culturally competent palliative care in the Qikiqtaaluk region of Nunavut

Health care providers' perspectives

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Abstract

Objective To explore health care providers' perceptions of the provision of palliative care in the Qikiqtaaluk (formerly known as Baffin) region of Nunavut.

Design An exploratory, qualitative, cross-sectional design using in-depth, semistructured interviews.

Setting Qikiqtaaluk region of Nunavut.

Participants Seven physicians and 6 registered nurses who worked in Iqaluit or other northern Inuit communities in the Qikiqtaaluk region of Nunavut.

Methods Thirteen health care providers participated in in-person or telephone semistructured interviews, which were audiorecorded and transcribed verbatim.

Main findings Interviews with the participating health care providers in the Qikiqtaaluk region of Nunavut revealed 5 complex and interwoven themes that influence the provision of comprehensive, culturally competent palliative care services to Indigenous patients: respecting Inuit culture, end-of-life care planning, and the role of family; recognizing the importance of the northern community (sense of home); being aware of the limited health care resources; recognizing the critical role of medical interpreters; and improving the quality of palliative care programs and resources, as well as health care provider training in palliative care and Inuit end-of-life care.

Conclusion Health care providers in the Qikiqtaaluk region of Nunavut have identified several important themes that influence the provision of culturally sensitive and comprehensive palliative care, most notably the need to develop palliative care resources and programs. It is hoped that the results of this study can be used to help guide palliative care strategies including program development and educational initiatives for health care providers. These initiatives can help build community capacity within a currently underserved population and improve end-of-life care services available to Nunavut patients and their families. Further studies are required to determine the perspectives of medical interpreters, as well as palliative care patients and their families.

Editor's key points

- ▶ Providing palliative care services in rural and remote communities in Canada such as the Qikiqtaaluk region of Nunavut can be both challenging and rewarding for health care providers. Interviews with health care providers who delivered palliative care services to Nunavummiut revealed several themes (eg, respecting Inuit culture, recognizing the importance of community), creating a framework to help guide the provision of palliative care to Indigenous patients in Nunavut.
- ▶ Participants described the importance of providing culturally sensitive palliative care by providing a holistic approach to care including an understanding of a patient's psychosocial, cultural, and spiritual background. They also explained the need to understand a patient's wishes and goals of care, including not having any preconceived notions about Inuit end-of-life care culture or rituals.
- ▶ Participants identified several factors that might help improve the quality of palliative care provided to Nunavut patients and their families by building on existing community resources and programs: the need for better continuity of care by health care providers for palliative care patients in remote communities, standardized palliative care guidelines for health care providers, and access to a specialist palliative care physician familiar with local palliative care programs and resources to support local health care providers.



Points de repère du rédacteur

► La prestation de services de soins palliatifs dans des collectivités rurales et éloignées du Canada, comme la région de Qikiqtaaluk, au Nunavut, peut être à la fois difficile et satisfaisante pour les professionnels de la santé. Des entrevues avec des professionnels de la santé qui ont fourni des services de soins palliatifs à des Nunavummiuts ont permis de dégager divers thèmes (p. ex. respecter la culture inuite, reconnaître l'importance de la collectivité) et de produire un cadre conceptuel pour aider à orienter la prestation des soins palliatifs aux patients autochtones du Nunavut.

► Les participants ont décrit l'importance d'offrir des soins palliatifs adaptés à la culture en adoptant une approche holistique à l'égard des soins, notamment par une compréhension des antécédents psychosociaux, culturels et spirituels du patient. Ils ont aussi expliqué la nécessité de bien comprendre les souhaits et les objectifs de soins du patient, sans avoir d'idées préconçues entourant la culture ou les rituels des Inuits en fin de vie.

► Les participants ont cerné divers facteurs susceptibles d'améliorer la qualité des soins palliatifs prodigués aux patients du Nunavut et à leur famille en misant sur les ressources et les programmes communautaires en place: la nécessité d'une meilleure continuité des soins par les professionnels de la santé pour les soins palliatifs aux patients dans les collectivités éloignées, des lignes directrices normalisées sur les soins palliatifs à l'intention des professionnels de la santé, et l'accès à un médecin spécialisé en soins palliatifs qui connaît les programmes et les ressources en soins palliatifs de la région pour soutenir les professionnels de la santé locaux.

Prestation de soins palliatifs complets et adaptés à la culture dans la région de Qikiqtaaluk, au Nunavut

Points de vue des professionnels de la santé

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Résumé

Objectif Explorer les perceptions qu'ont les professionnels de la santé de la prestation des soins palliatifs dans la région de Qikiqtaaluk (connue auparavant sous le nom de Baffin), au Nunavut.

Type d'étude Une conception d'étude exploratoire, qualitative et transversale, à l'aide d'entrevues semi-structurées approfondies.

Contexte Région de Qikiqtaaluk, au Nunavut.

Participants Sept médecins et 6 infirmières autorisées qui ont travaillé à Iqaluit ou dans d'autres collectivités inuites nordiques dans la région de Qikiqtaaluk, au Nunavut.

Méthodes Treize professionnels de la santé ont participé en personne ou par téléphone à des entrevues semi-structurées qui ont été enregistrées sur bande audio, puis transcrites textuellement.

Principales observations Les entrevues avec les professionnels de la santé participants dans la région de Qikiqtaaluk, au Nunavut, ont permis de cerner 5 thèmes complexes et entrecroisés qui influent sur la prestation de services de soins palliatifs complets et adaptés à la culture aux patients autochtones: respecter la culture inuite, la planification des soins en fin de vie et le rôle de la famille; reconnaître l'importance de la communauté nordique (sentiment d'être chez soi); être au fait des ressources limitées en matière de santé; reconnaître le rôle essentiel des interprètes médicaux; et améliorer la qualité des programmes et des ressources en soins palliatifs, de même que la formation des professionnels de la santé en soins palliatifs et en fin de vie pour les Inuits.

Conclusion Les professionnels de la santé dans la région de Qikiqtaaluk, au Nunavut, ont cerné plusieurs thèmes importants qui influent sur la prestation de soins palliatifs complets et adaptés à la culture, plus particulièrement la nécessité de développer les ressources et les programmes en soins palliatifs. Il est à espérer que les résultats de cette étude puissent servir à orienter les stratégies sur les soins palliatifs, y compris l'élaboration de programmes ainsi que d'initiatives éducatives à l'intention des professionnels de la santé. Ces initiatives peuvent contribuer à renforcer les capacités communautaires au sein d'une population actuellement mal desservie et à améliorer les services de soins en fin de vie accessibles aux patients du Nunavut et à leur famille. D'autres études sont nécessaires pour déterminer les points de vue des interprètes médicaux, de même que ceux des patients en soins palliatifs et de leur famille.

Geographic challenges have been identified with respect to the provision of palliative care services to First Nations, Inuit, and Métis patients and their families in rural and remote communities in Canada.^{1,2} Palliative care services and programs in Canadian rural and remote communities remain limited, and information on the rate of use of programs is largely unknown. In addition, there are currently no guidelines for providing palliative care services to Indigenous people in Canada. Health care providers in Nunavut must consider a patient's sociocultural background, including the legacy of colonization and residential schools, in providing holistic palliative care to Nunavut patients and their families.³

Rather than establishing a broad set of standard guidelines, there is growing recognition that palliative care program development and service delivery should build on existing community strengths to meet the individual needs of rural communities.⁴ This is demonstrated through qualitative studies that have subsequently informed the development of palliative care programs within their specific regions; examples include a 2013 study that examined service providers' perspectives on improving palliative care outcomes for Indigenous people in Australia,⁵ and a 2017 qualitative study by Hordyk et al that explored the provision of end-of-life care to Inuit patients and their families in Nunavik, Que.⁶ This study helped to develop a sustainable model of palliative care for the region.⁶ One model described by Kelly conceptualizes the process of developing rural palliative care services and programs through community capacity development using 4 sequential phases.⁷ Local health care providers play a critical role in providing palliative care services in rural communities but their training might be inadequate, with limited studies exploring their perceptions and needs.^{2,8}

At the time of the study, the Qikiqtaaluk (formerly known as Baffin) region of Nunavut did not have a formal palliative care program. Rather, palliative care was being provided within the community or at the Qikiqtani General Hospital (QGH) in Iqaluit, NU, or within a patient's home in one of the Qikiqtaaluk region's communities supported by the local health centre. Patients with complex symptoms or those requiring specialty referral to medical or radiation oncology were referred to the Ottawa Hospital Cancer Centre in Ontario.

The primary objective of this study was to explore health care providers' perspectives on the provision of palliative care in the Qikiqtaaluk region of Nunavut, further examining their understanding of and experiences with providing palliative care services to Indigenous patients. This study also aimed to identify factors that influence the provision of palliative care and to determine ways in which the quality of current palliative care programs and services could be improved for Nunavut patients and their families. Critical to follow are studies that explore the perspectives and voices of local

community members, patients and their families, and Inuit medical interpreters in helping to improve the quality of palliative care services.

— Methods —

Study design

An exploratory, qualitative research approach using semi-structured interviews was used to explore the perspectives of individual health care providers in the Qikiqtaaluk region. Drawing on a constructivist paradigm that emphasizes the importance of engaging directly with participants to further examine what they know about, how they understand, and how they make meaning of their experiences,^{9,10} this study was designed to gather in-depth information on what health care providers know about providing palliative care to Indigenous patients, as well as on how they understand and make meaning of their experiences in the provision of this care to these patients. One-on-one interviews allowed participants to share emotional clinical experiences that could be difficult to share using other qualitative methods, such as focus groups. Ethics approval was obtained from the Bruyère Continuing Care Research Ethics Board, the Ottawa Health Science Network Research Ethics Board, and the Nunavut Research Institute.

Research sites

The Qikiqtaaluk region is the most populated and eastern region of Nunavut with a population of approximately 16 000 people.¹¹ Approximately half the population lives in Iqaluit, and the other half in 12 remote communities. The QGH in Iqaluit is a 35-bed acute care facility serving the Qikiqtaaluk region.

Participants

Health care providers included physicians and registered nurses and were recruited through a research study recruitment e-mail and a poster at the QGH. Informed written consent for participation and audiorecording was obtained.

Data collection

Information on participants' health care provider role (physician or registered nurse), as well as length of time spent working in Nunavut, was collected at the time of the interview. In-depth interviews ranged from 20 to 40 minutes and were completed by the principal investigator (D.V.) to enhance consistency.

An interview guide was developed for this study through an iterative process based on themes identified in the literature and feedback received by members of the research team, staff at the Nunavut Research Institute, and a local physician in Iqaluit. To retrieve a copy of the interview guide, contact the corresponding author (D.V.). The principal investigator (D.V.) completed

information gathering through field notes, and interviews were digitally recorded and transcribed verbatim.

Data analysis

Interview transcripts were transcribed and reviewed for accuracy, and NVivo software was used for data analysis. Drawing on an iterative process, transcripts were coded thematically¹²⁻¹⁴ by the principal investigator (D.V.) and by a second member of the research team (J.C.). Thematic analysis identified patterns, themes, and sub-themes within the data. Discrepancies in coding between coders were reviewed and reconciled. Rigour and trustworthiness were maintained and verified throughout the course of the study by drawing on research responsiveness that was documented with a field journal and audit trail.¹⁵ Coherence across the data was verified by drawing on thick description of codes, and was further maintained by having 2 research team members iteratively code all of the data (D.V., J.C.). Continued, iterative exploration across the data reflected that the collected data that were comprehensive, trustworthy, and complete.¹⁴

— Findings —

Thirteen health care providers (7 physicians and 6 registered nurses) contacted the principal investigator (D.V.) to participate in the study. The average amount of time the health care providers had worked in Nunavut was 4 and half years for physicians and 10 years for registered nurses. All physicians had experience providing palliative care services in Iqaluit and in 1 or more remote communities in Qikiqtaaluk region. Five registered nurses had experience working in Iqaluit in multiple clinical settings, and 1 had worked in both Iqaluit and a remote Baffin Island community. One participant self-identified as Indigenous. In order to ensure confidentiality for study participants, health care provider quotes were assigned interview participant numbers and were not broken down further into subdisciplines.

Themes

Five complex and interwoven themes emerged from content analysis of the transcripts. Themes were used to develop a framework to guide health care providers in providing comprehensive, culturally sensitive palliative care services to patients and their families in the Qikiqtaaluk region of Nunavut.

Respecting Inuit culture, end-of-life care planning, and the role of family. Participants emphasized the importance of providing culturally sensitive palliative care by respecting patients' wishes and goals of care, and the importance of not having any preconceived notions about Inuit culture or rituals. A participant said, "Not applying the same values or my values or goals So, I think respecting those choices." (Interview 12)

Participants often noted a reluctance or conscious decision by patients and families to not discuss goals of care or end-of-life care planning.

[The] conscious decision to not talk about it [goals of care and end-of-life care planning] is probably the biggest barrier that I've encountered. (Interview 13)

A barrier that I've encountered is just different cultural expectations. Some Elders believe that this is a private experience and sometimes symptoms they just are to be suffered through, and sometimes people are reluctant to ask for help with symptom management. There's a lot of people that just don't like to discuss end-of-life issues and it's not really something that I think is traditionally discussed and planned for in advance as much as maybe in some other cultures. (Interview 13)

In addition, many participants mentioned the critical role of family and extended family in Inuit culture for support and decision making.

I think family tends to be a very important thing and lots of people want their families around and the families want to be around, so that kind of supportive family environment. (Interview 13)

Extended family is a very important part of Inuit culture in general, I think, especially at the start of life and at the end of life; we see that a great deal and we try and accommodate that as much as possible. (Interview 5)

Recognizing the importance of the northern community (sense of home). Participants described the importance of community for Inuit patients and their families, noting a strong desire by patients to receive medical care at home or in their home communities.

What I've witnessed is just a very strong desire by the patients and their families to want to be cared for at home. I don't know if one would call that culturally sensitive, but that's just the overwhelming theme I've seen time and time again, as they do want to live and die in their home surroundings and environment with their families present. (Interview 2)

Working in Iqaluit, one of the big things is also geographically sensitive care, as well. So, there are certain patients that definitely feel more comfortable being in a hospital setting, where others would much rather be at home, and that's something I would say really differentiates palliative care here from a lot of other places. (Interview 13)

Participants also outlined multiple issues that need to be considered by health care providers when helping

patients and families with life-limiting illnesses make treatment decisions based on their goals of care, especially regarding possible transfer outside of their communities in Nunavut for further investigations or treatments.

The difference here compared to other places is often what gets the conversation going is often you have to talk about—in addition to what their code status is—you have to talk about whether they want transfer or not, whether they want transfer to Ottawa, whether they want transfer to Iqaluit. I do often have to talk about how far they would really be willing to be transferred for their goals of care. (Interview 6)

Culturally speaking, the Elders want to die where they lived. They want to be with the family when they pass on, and a lot of the Elders [we have seen] recently have been refusing to go to Ottawa because they know there's a chance if they go down, they're not coming back; and if they're told that a lot of them will refuse to go to Ottawa because they want to die on their own terms, in the community. (Interview 1)

Being aware of the limited health care resources.

Participants described the effect of limited resources on their ability to provide palliative care in the Qikiqtaaluk region of Nunavut, which was believed to be a concern in most remote northern communities. Participants noted Inuktitut interpreters were often not available at the QGH in Iqaluit and that they had to rely on other health care providers or most often patients' family members for interpretation.

I think the big thing ... for palliative care is the effect of distance and how great that is and how important for many, many people it is to be able to have care close to home. So, whatever services are provided in palliative care ... I think we need to be cognizant of the realities of those communities and the limited resources they have and may be available. (Interview 1)

We don't always have interpreters available and if the family's not comfortable discussing it [goals of care and end-of-life care planning] with their loved one, then it's a very difficult conversation to have. It's almost impossible if we don't have an interpreter and we go without interpreters fairly often. So that's definitely been a barrier. (Interview 5)

Recently, we've had a few more interpreters, but I probably work 80% of my shift without one and that's a huge safety issue all on its own. When it comes to clinical conversations like code status and end-of-life planning, you know it's impossible to do it if you can't speak the language. (Interview 5)

Recognizing the critical role of medical interpreters.

Participants described the critical role of Inuit interpreters as members of the palliative care multidisciplinary team. Participants identified a need to better support and educate interpreters in their approach to palliative care, advance care planning, and goals of care.

I think it's really important that you have a skilled interpreter who's comfortable having those conversations. (Interview 13)

I certainly don't want to feel like we are forcing them to have a conversation that they may not want to have personally or culturally, but I feel that we're not even getting the point across as to why we want to have the conversation. If the interpreters can be educated in that, that would be a huge help to us. (Interview 8)

Participants also reported that Inuit medical interpreters were often uncomfortable discussing advance care planning, including recommendations against cardiopulmonary resuscitation and end-of-life care planning.

I think it's one area that does pose a bit of a barrier Even if I talk a bit of Inuktitut, I still would not be able to have a good discussion around this in someone's first language. And so we rely a lot on the interpreters, but I think it's an extremely challenging thing for them. (Interview 12)

Finally, participants described their experiences using family members as interpreters when no medical interpreter was available. Participants often noted reluctance by family members to discuss goals of care and end-of-life care planning with health care providers.

I try not to use family members for palliative care conversations even more specifically than other things because of the reluctance of people to discuss some of these issues, and when you're having a palliative care discussion, code status, goals-of-care discussion, you really want to make sure that the information that is being delivered to the patient is accurate and complete. So if there's nobody around, I will use family members, but that's certainly a last resort. (Interview 13)

What I've seen a lot of is families fairly reluctant to have a discussion with a loved one that is dying, and sometimes the discussion is had at the point where the patient has already suffered and they could have benefited from a more formal, organized palliative care plan. (Interview 5)

Improving the quality of palliative care programs and resources, as well as health care provider training in palliative care and Inuit end-of-life care. Participants identified several ideas for improving the quality of palliative care

provided to patients and their families by building on existing community resources and programs. Ideas for quality improvement included the need for better continuity of care by health care providers for palliative care patients in remote communities, standardized palliative care guidelines for health care providers, and access to a specialist palliative care physician familiar with local palliative care programs and resources to support local health care providers.

It's still a bit patchy in terms of provider coverage for the small communities. (Interview 12)

I think we need a little bit more of a standard of care for a palliative approach. Right now, people are adopting whatever measures they've learnt from the south and brought them up north, so those vary, and I'm a fan of standardized care, so everyone's on board and everyone gets good treatment. (Interview 4)

Would certainly be ideal if we had more access to a full-time palliative care physician or who covers Nunavut as a whole through telehealth. The GPs who work here who all have varying degrees of experience and comfort with palliative care as well as all of the outpost nurses, if they could have access to that, that would be great, too. (Interview 8)

Participants believed that members of the palliative care multidisciplinary team would benefit greatly from additional training and education in advance care planning, goals-of-care discussions, a palliative approach to care, and providing culturally sensitive end-of-life care for Nunavummiut by understanding their sociocultural background. Participants had various types of previous training and education in palliative care, and no participants had received any previous formal education or training in Inuit culture or end-of-life care.

We need more education, because unless you come here with a palliative care background, this ain't the place you're going to get it. So, a bit of, you know, the mindset of palliative care—the assessments involved in palliative care. (Interview 9)

I think we could all benefit from that [education on providing culturally sensitive end-of-life care for Nunavummiut], and I think it's almost imperative to integrate that into our orientation for all our new hires, too, to understand where people have come from, where they are today, and what their needs are. (Interview 4)

— Discussion —

Providing palliative care services in rural and remote communities throughout Canada, including the

Qikiqtaaluk region of Nunavut, can be both challenging and extremely rewarding for health care providers. Participants described the importance of providing culturally sensitive palliative care by providing a holistic approach to care including an understanding of a patient's psychosocial, cultural, and spiritual background. In addition, participants described the need for health care providers to understand a patient's wishes and goals of care, including not having any preconceived notions about Inuit end-of-life care culture or rituals. Shahid et al also described the need for health care providers to recognize that cultural practices related to death and dying among Indigenous Australians varied among different patients and their families.⁵

The importance of community (sense of home) for Inuit patients and their families in Nunavut was a prominent theme. Participants described a strong desire by Inuit patients and their families to receive end-of-life care in their home communities. Our findings are consistent with those of qualitative studies by Hordyk et al and Hotson et al, which found that patients living in remote or northern communities preferred to receive end-of-life care in their home communities.^{6,16} Participants frequently described rewarding experiences helping patients and families with life-limiting illnesses make treatment decisions consistent with their goals of care, including difficult discussions regarding possible transfer outside of their home communities to Iqaluit or outside of Nunavut for further investigations or treatments. A similarly designed study exploring service providers' perspectives on how to help improve palliative care outcomes for Indigenous Australians described the complexity of discussions about death and dying and goals of care with patients with life-limiting illnesses.⁵ The authors also highlighted the importance of providing culturally sensitive palliative care using an interdisciplinary approach, which is in keeping with our study findings.

Participants described the critical role of Inuit interpreters as members of the palliative care multidisciplinary team in Nunavut. Recognizing this important role, participants identified the need to better support and educate interpreters in palliative care. Participants described medical interpreters as often being uncomfortable discussing goals of care and advanced care planning. In addition, participants noted that Inuit medical interpreters were often not available and noted a reluctance by family members to discuss goals of care and end-of-life care planning with health care providers when no interpreter was available. Participants did not provide insight into why they believed interpreters were often not available and were uncomfortable having goals-of-care discussions, but recognized the need to determine their perspectives. A qualitative study by Kelly et al of bereaved First Nations family members similarly described the important role of medical interpreters when having goals-of-care discussions with

patients, and noted that interpreters had limited training in palliative care and were therefore understandably uncomfortable having these difficult conversations.¹⁷

Finally, participants in our study described the importance of developing educational initiatives for palliative care and building on the existing resources and programs to increase the quality of end-of-life care services available to Nunavut patients and their families. Participants believed that all members of the palliative care multidisciplinary team would benefit greatly from additional training and education in palliative care and on how to provide culturally sensitive end-of-life care for Nunavut patients by understanding their sociocultural background.

Limitations

The health care providers' views represent their personal understandings and experiences of providing palliative care in the Qikiqtaaluk region of Nunavut. For this reason, the results might not be transferable to other health care providers in other Indigenous communities.¹⁸ A cross-sectional design was used owing to the time-limited data collection window used within this study. While having worked previously in the Qikiqtaaluk region of Nunavut, the principal investigator (D.V.) conducted all the in-person interviews during a 2-week period in Iqaluit before data review and analysis. While rigorous analytic approaches were used, it is important to highlight that a research design that used prolonged engagement might identify differing findings and experiences across a broader sample of health care providers.¹⁴ Owing to the specific scope of the study and time and resource limitations, study participants only included health care providers. In order to obtain a more complete understanding of palliative care service provision in Nunavut, the perspectives of medical interpreters and Inuit patients and their families need to be explored.

Conclusion

Our study is the first to explore the provision of palliative care services to Nunavut patients and their families using qualitative research methods. By determining the perspectives of health care providers, 5 complex and interwoven themes emerged, creating a framework to guide health care providers in providing comprehensive, culturally competent palliative care services in the Qikiqtaaluk region of Nunavut. Health care providers highlighted the need to develop a palliative care program within Nunavut that builds upon existing local programs and resources. Further studies examining the perspectives of Nunavummiut and their families, as well as medical interpreters, are needed. We hope our study results will help guide palliative care strategic planning in Nunavut, including program development and educational initiatives for health care providers, helping to build local community capacity, provide better care, and improve end-of-life care for patients and their families. 🌱

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Contributors

Dr Vincent was the principal author and drafted the main research protocol, conducted the literature review and ethics board application, conducted all interviews, completed the coding of transcripts for themes and initiated the analysis of the data, and took the final responsibility for drafting the manuscript. **Dr Rice** provided overall project supervision, contributed to the design of the research protocol, and assisted with data interpretation and revisions of drafts of the manuscript. **Dr Chan** coded transcripts for themes, helped with data analysis, and reviewed drafts of the manuscript. **Dr Grassau** provided co-supervision on the project, expertise in qualitative research methods for the design of the study and contributed to data analysis and drafting of the manuscript.

Competing Interests

None declared

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