



UNIVERSITY OF  
TORONTO



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# Nunavut End-of-Life and Cancer Care Study: Patient and Community Member Perspectives

# Disclosure Statement

- I have no affiliation (financial or otherwise) with a pharmaceutical, medical device or communications organization.

# BACKGROUND

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- Nunavut community members highlighted a need for appropriate, culturally-sensitive cancer and end-of life care for Nunavummiut

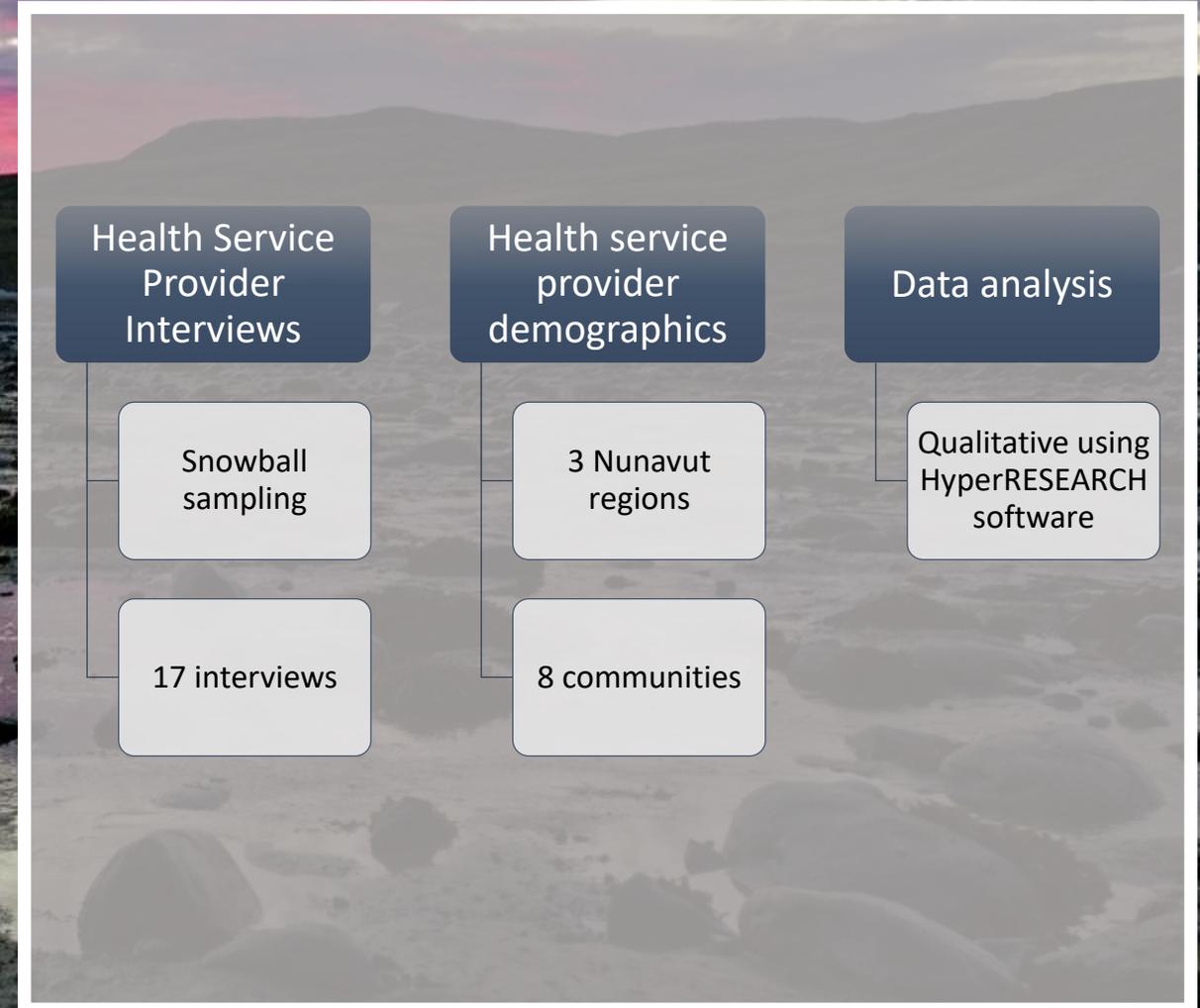
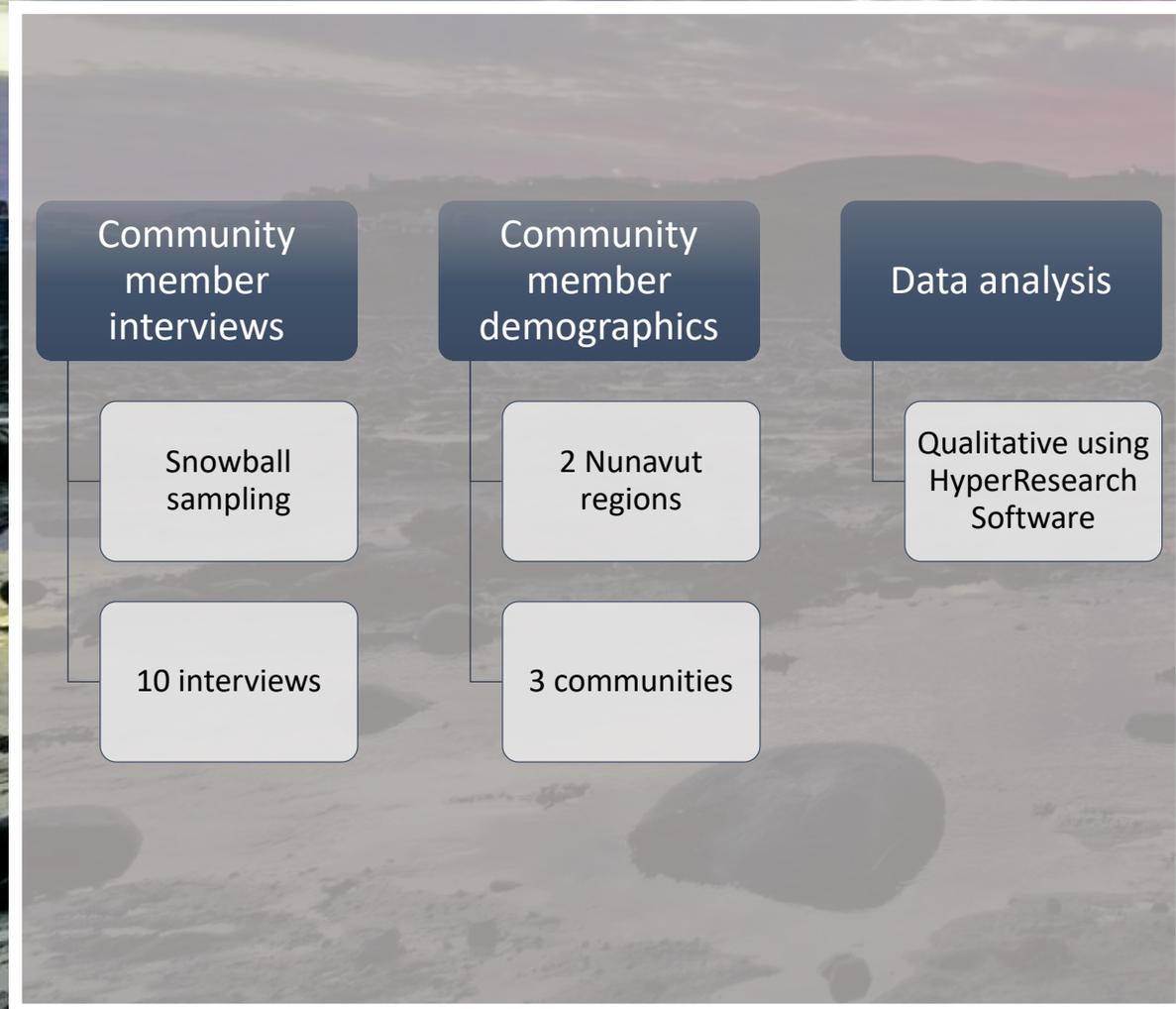
## Purpose

- Understand the existing cancer and end of life care supports available for Nunavummiut, and how these supports can be improved to deliver the type of care Nunavummiut would prefer

## Objectives

- Understand the experiences of families who have faced or are currently facing end of life decisions
- Understand the experience of Nunavut patients who are diagnosed with cancer and are referred to treatment
- Examine what networks exist in communities that can support patients and families

# METHODS



# THEMES – Community Member Perspectives



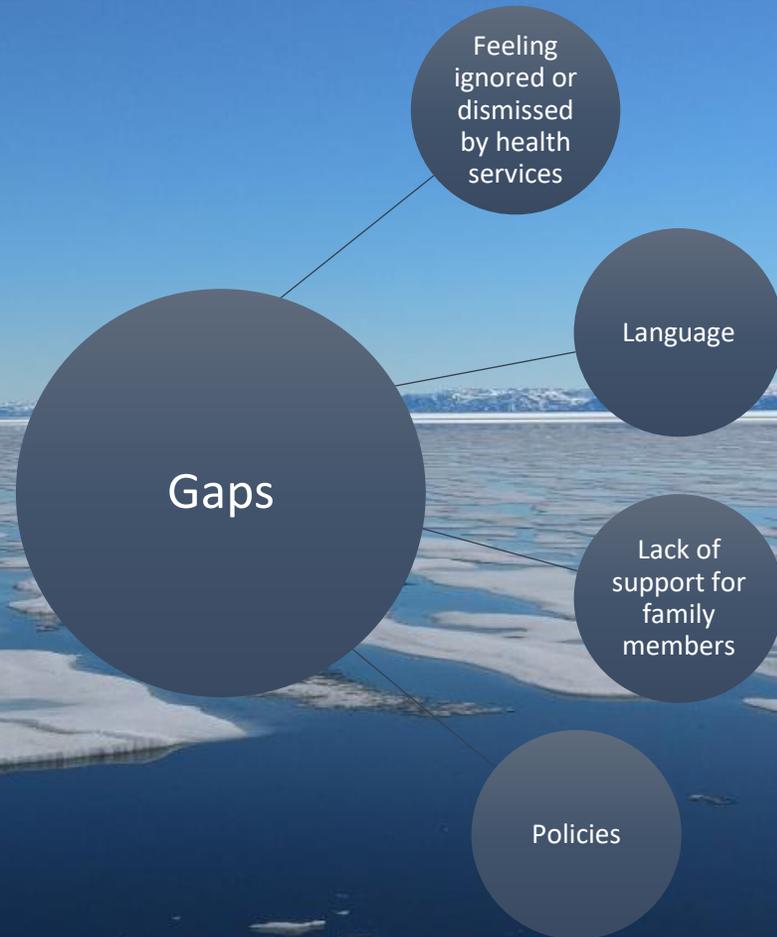
# STRENGTHS



# CONTEXTUAL FACTORS



# GAPS/ISSUES



# Feeling Ignored or Dismissed by Health Services

“

*So, we knew there was something wrong with my mom...she was in and out [the] ER and they'd just prescribe Tylenol and say 'of come back next week'*

”

# Language

“

*They need to be able to listen to what somebody's saying. If there's a language barrier, then that's when you bring an interpreter in....have them point to where it hurts. If they had done that with my grandmother, I think they would have been able to catch the cancer sooner than they had done.*

”

# Lack of Support for Family Members

“

*I felt so alone and I felt so helpless and they didn't even provide us any instructions on how to take care of a cancer patient. It was just all I know is that there was some foods that she couldn't eat...there was some food that she couldn't digest...but we weren't ever instructed as to how to take care of her – what to do if something happened. We were just left on our own*

”

# RECOMMENDATIONS



# Make Full Time Counseling Available

“

*“I feel like just being able to talk about it is really helpful because I’ve never really talked about it to other people besides my immediate family and a mental health worker”*

”

# Improved Communication with Family

“

*“The doctors speak in this very...scientific [way], medical terms that oftentimes I’d be like, “What...are you saying?” Honestly. You remember you’re talking to humans who don’t understand.”*

”

# More Support for Family Caretakers

“

*“The other barrier we have is... there’s no respite care. So, there’s really no... respite for families to say like okay this person will be at this place – your home for a certain amount of time...if there were people who were trained to give respite care that would help the overall accepting of palliating someone at home because it’s - it’s tough on the family. It’s tough on the person...people need breaks”*

”

# THEMES – Health Service Provider Perspectives

Experiences of patients and families

Personal, local, and systemic determinants of a positive experience of cancer/EOL care

Barriers to quality of life/death for patients and families

Difficulties providing care for health care professionals

Cultural considerations and reflections

Suggestions for improving quality of care

# PERSONAL, LOCAL, AND SYSTEMIC DETERMINANTS OF A POSITIVE EXPERIENCE OF CANCER OR END OF LIFE CARE



Religion/spirituality

Involvement &  
role of the family

Home care  
program

# BARRIERS TO QUALITY OF LIFE/DEATH FOR PATIENTS/FAMILIES

“

*I remember one time I had a client, he had a tumour. He went down with his wife and they are both unilingual, and his understanding was that the tumour was getting smaller, but they were told it was getting bigger and spreading... So sometimes there is a disconnect from what they are told and what they actually understand.*

”

# DIFFICULTIES PROVIDING CARE FOR HEALTH CARE PROFESSIONALS

“

*It brings sadness, because you know you're going to bring bad news to the family, but at the same time, you also... feel like you want to provide as much support as you can provide. Overall, to me though, it's sadness. I've had situations where I've cried and cried with the family, because these are the same persons we go hunting or we hang around or we go to the arena when there are activities. So they're like family too, on top of it.*

”

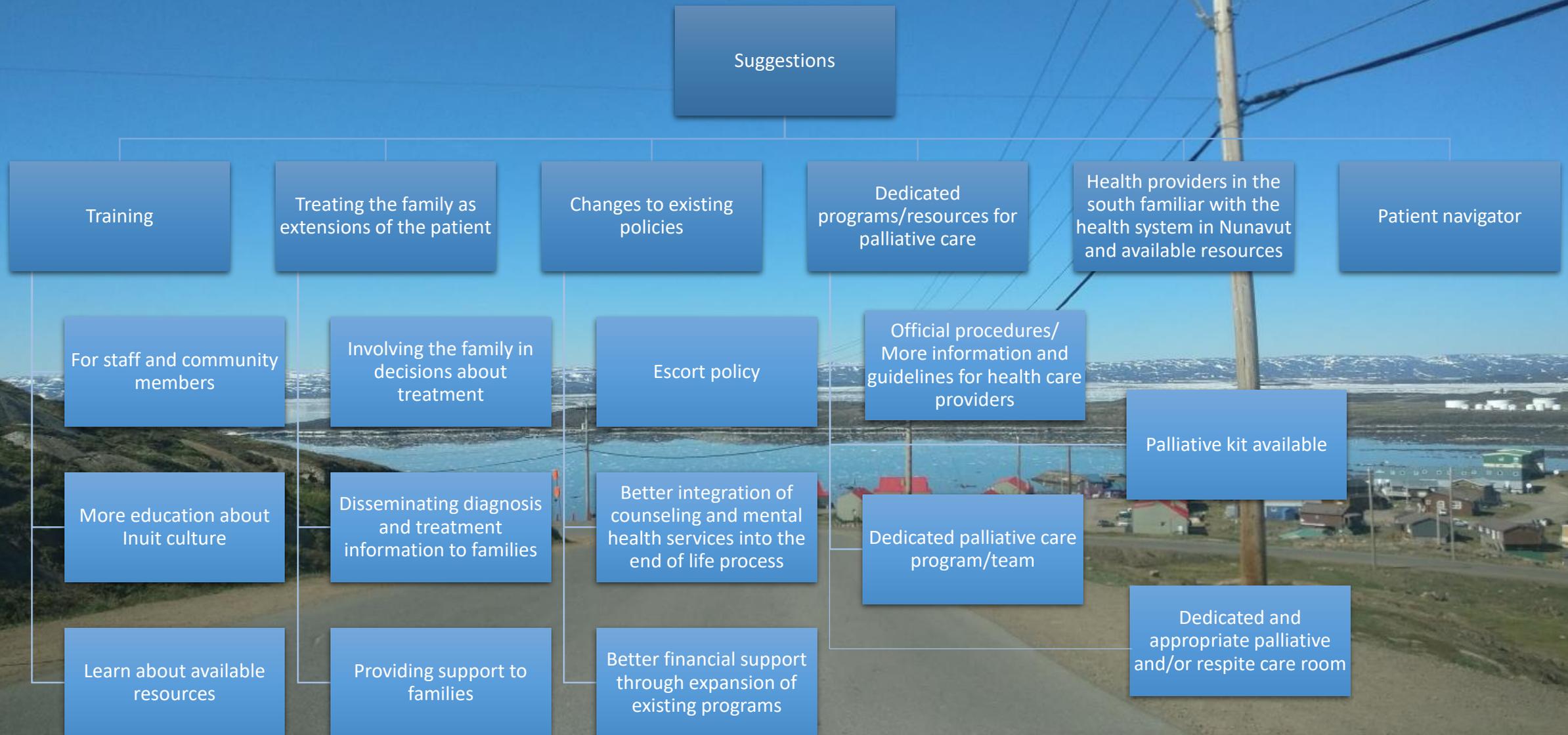
# CULTURAL CONSIDERATIONS AND REFLECTIONS

“

*“Usually how it works in the community is that an elder in town is usually the person who you will call when the patient is close to death, passing away, or passed away. This elder is supposed to help you communicate with the family, explain what to do with the body, how to respect the community and respect the people, just explain how it works for them. That was really good for me, because I didn’t have a clue of what I should be doing or not doing.”*

”

# SUGGESTIONS FOR IMPROVING QUALITY OF CARE



# Training



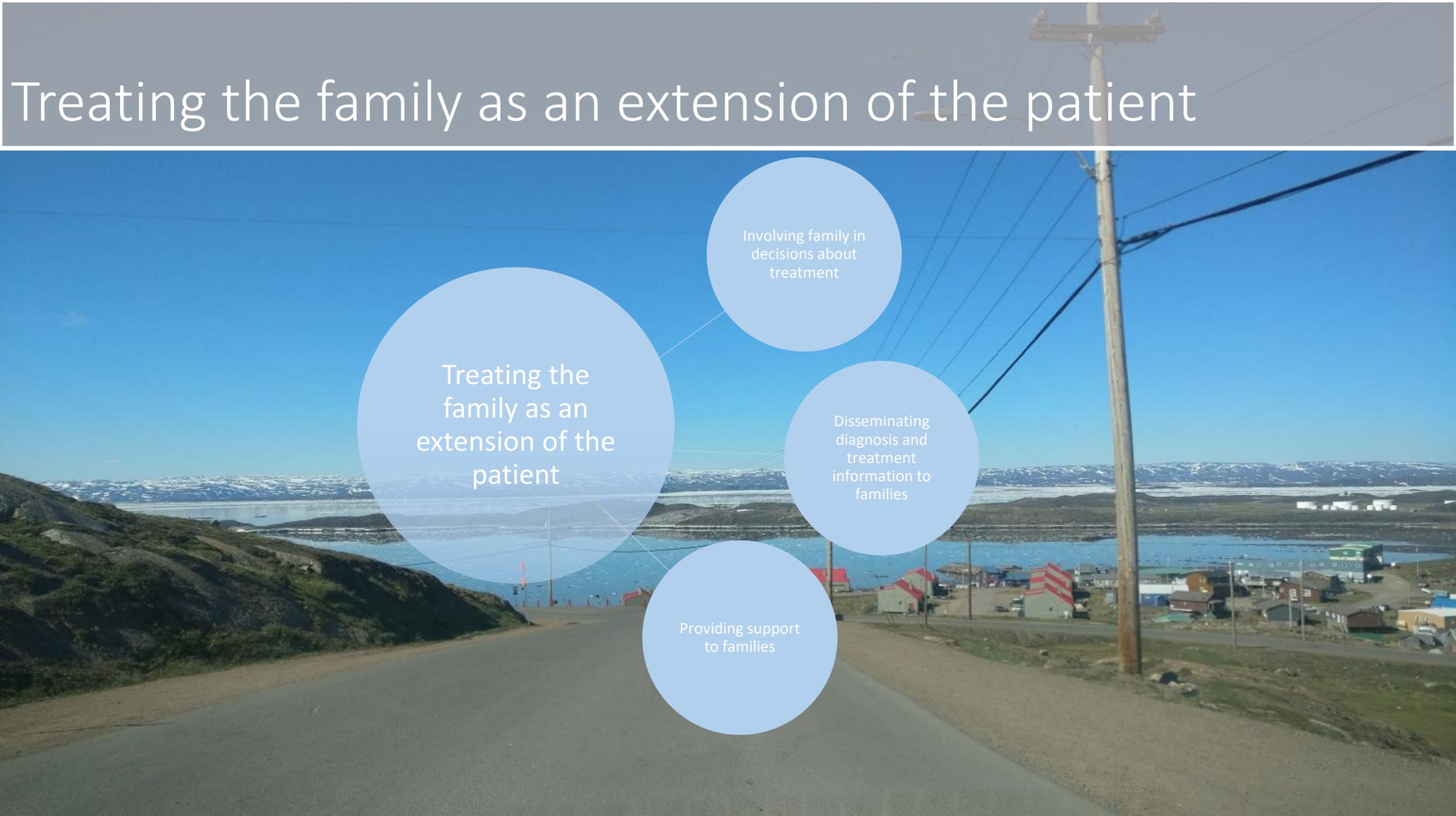
# Treating the family as an extension of the patient

Treating the family as an extension of the patient

Involving family in decisions about treatment

Disseminating diagnosis and treatment information to families

Providing support to families



# Treating the family as an extension of the patient

“

*The palliative orders are usually very simple; they're usually pain control. And comfort measures. The patient at that point, of course they are the patient, they are important, but the extensions of the patient - which is the family - is where your work is. Your real work is.*

”

# Changes to existing policies

Changes to existing policies

Escort policy

Better integration of counseling and mental health services into the end of life process

Better financial support through expansion of existing programs



# Dedicated programs and resources for palliative care

Dedicated programs and resources for palliative care

Official procedures/ More information and guidelines for health care providers

Palliative kit available

Dedicated palliative care program/team

Dedicated, appropriate, palliative room or respite bed for patients

# Thank you!



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