



UNIVERSITY OF
TORONTO



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

Background

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

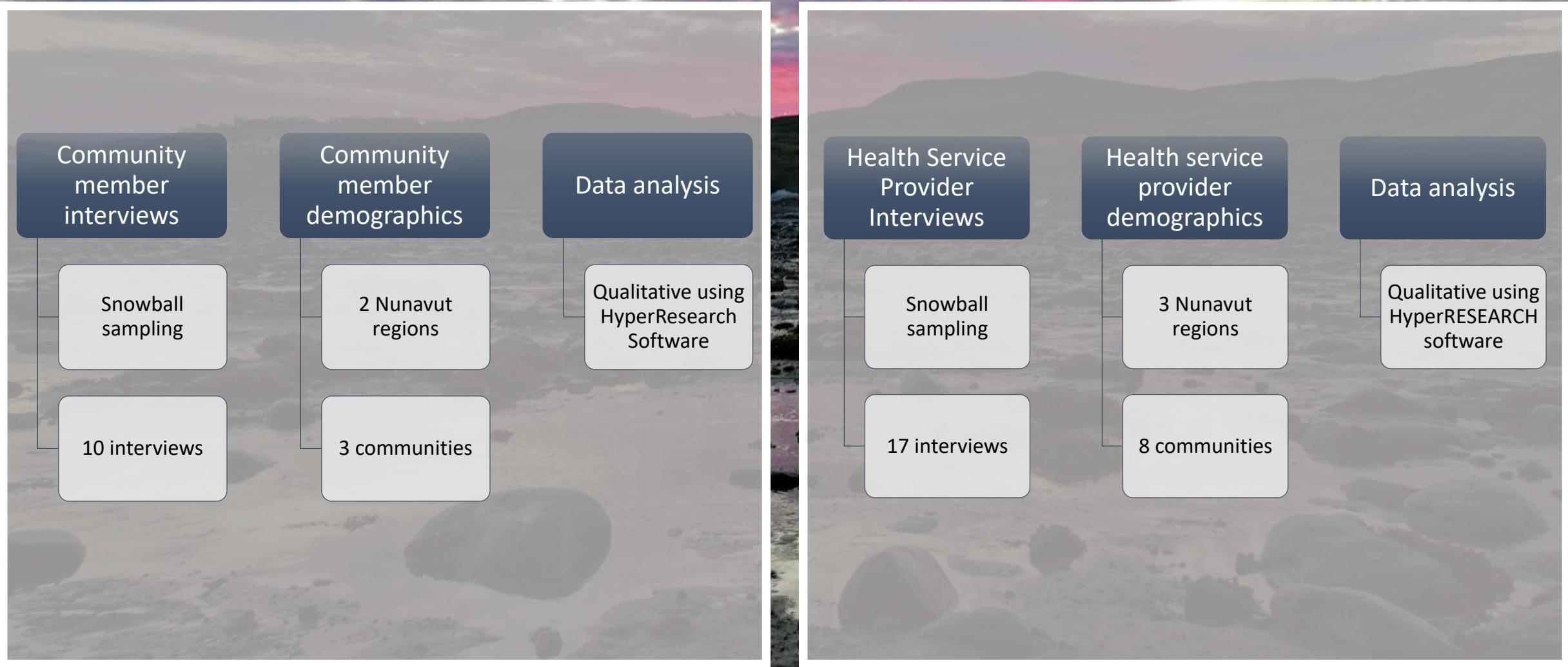
Purpose

- 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

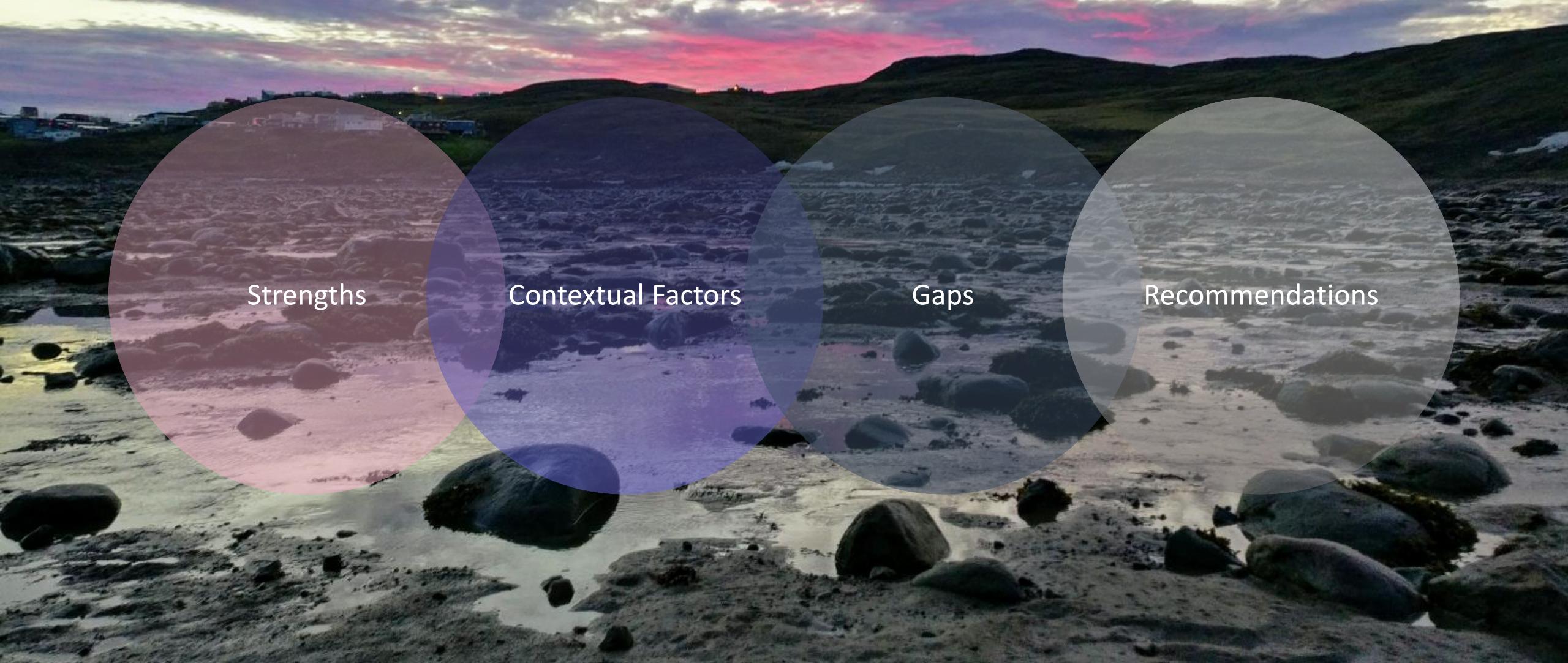
Objectives

- 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



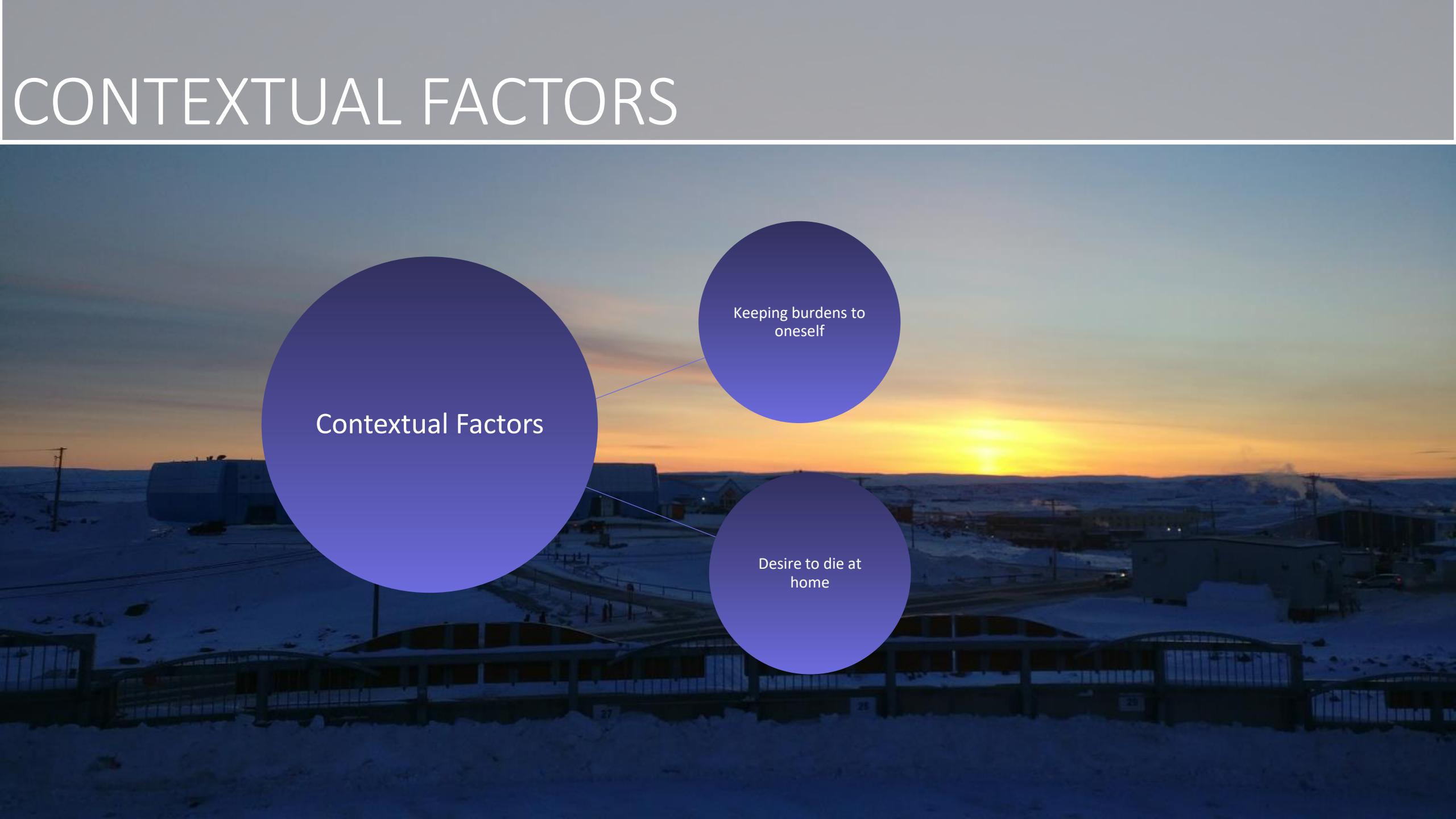
THEMES – Community Member Perspectives



STRENGTHS



CONTEXTUAL FACTORS



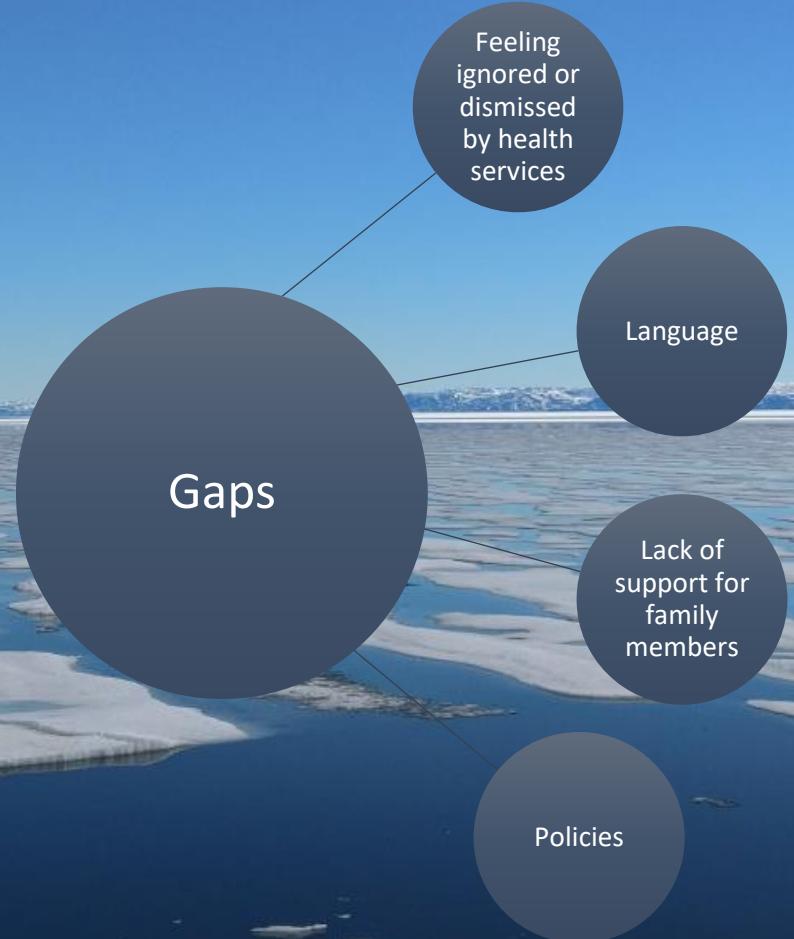
The background image shows a wide, snow-covered landscape with several industrial buildings and structures under a sky transitioning from blue to orange and yellow at sunset.

Contextual Factors

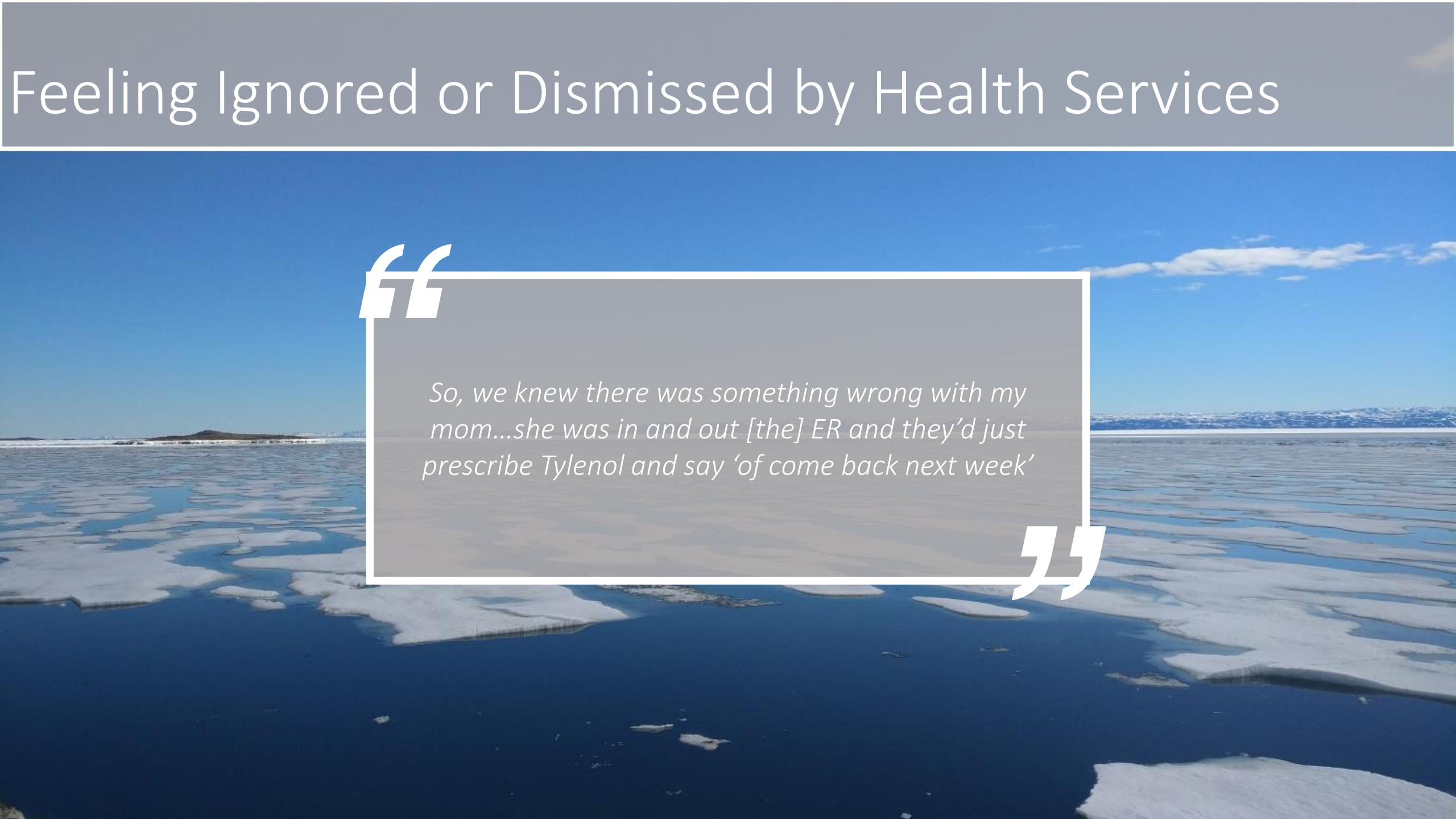
Keeping burdens to oneself

Desire to die at home

GAPS/ISSUES

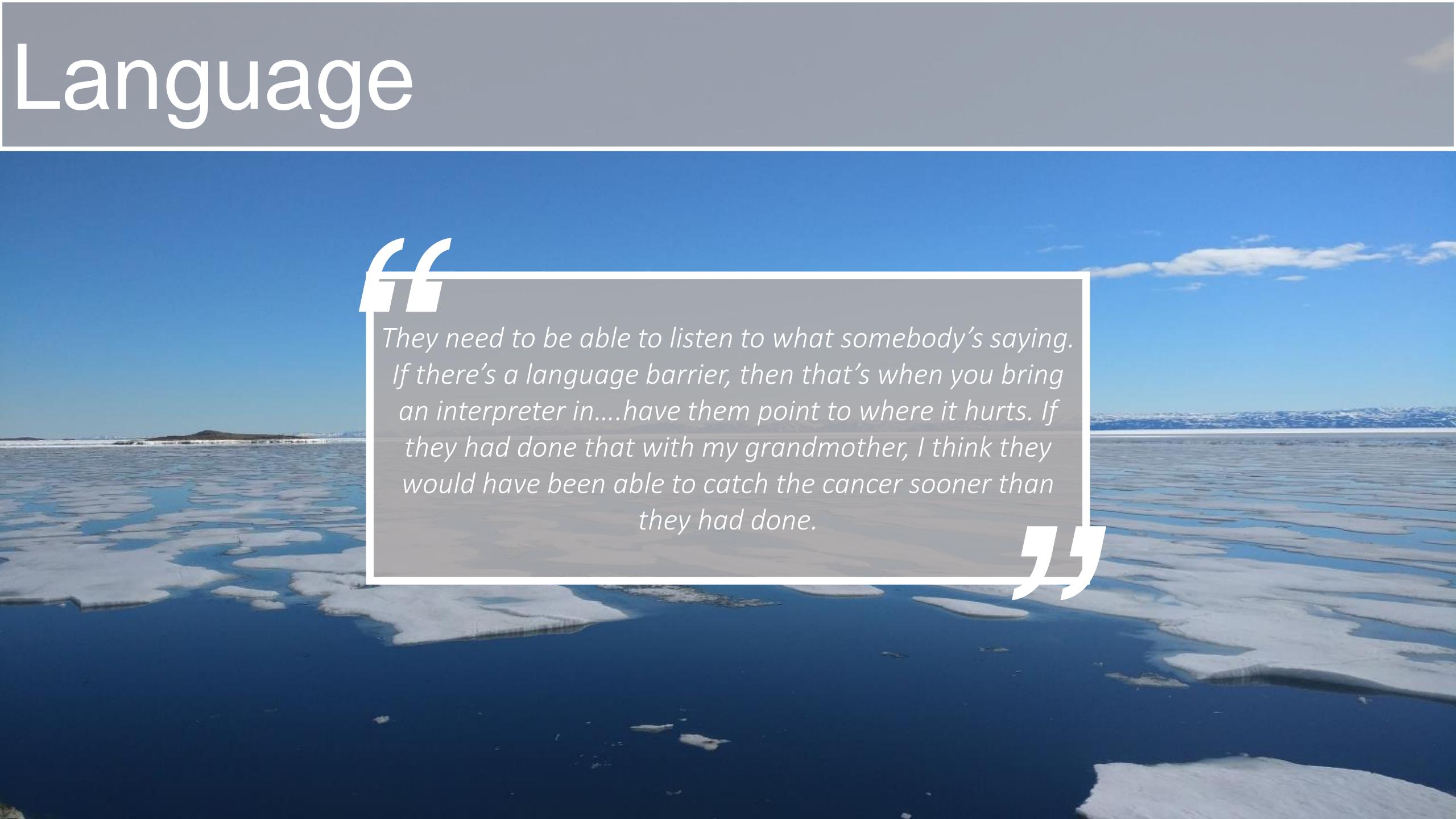


Feeling Ignored or Dismissed by Health Services



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



Recommendations

Make full time
counseling
available

Improved
communication
with family

More support for
family caretakers

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

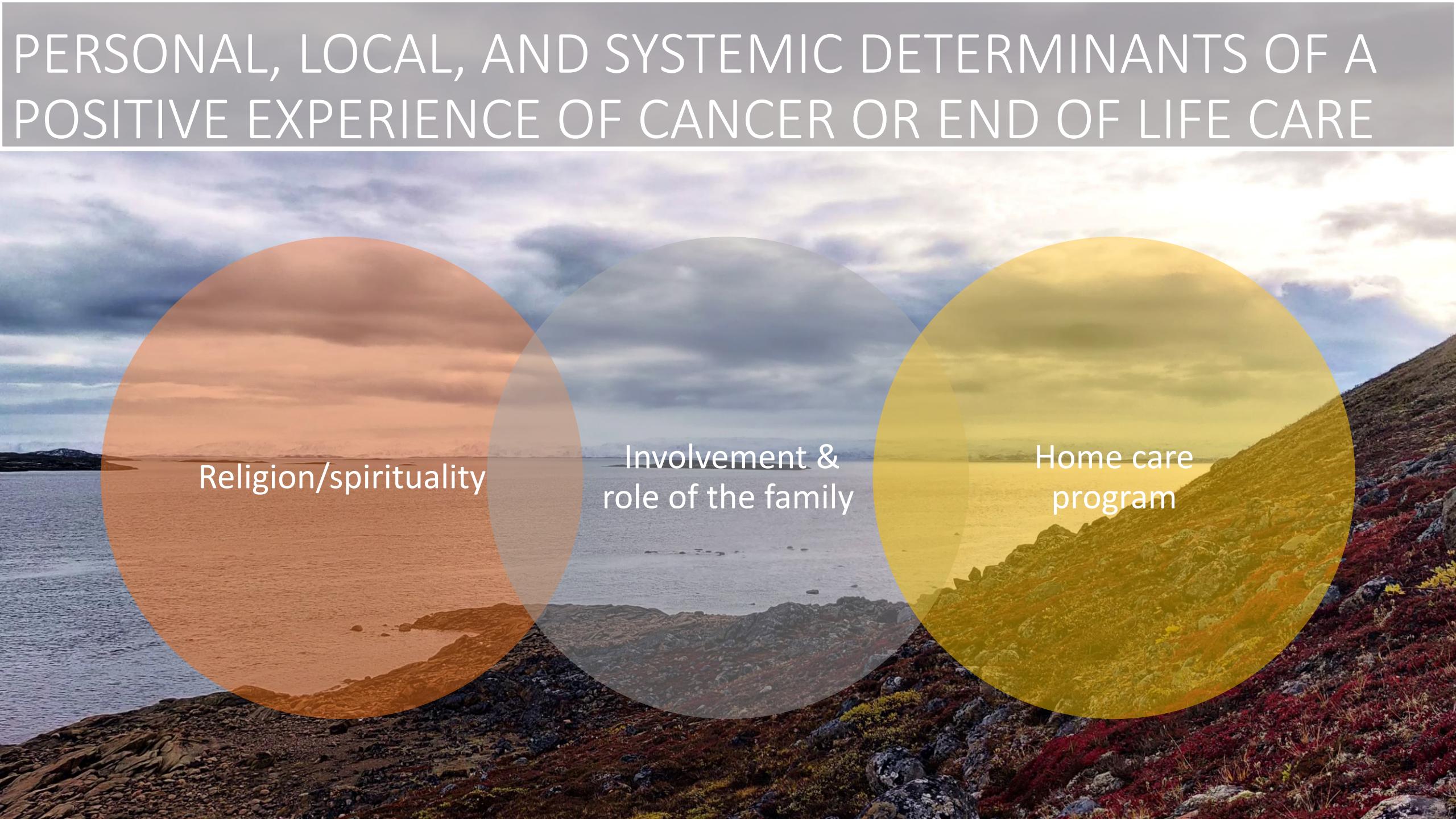
Barriers to quality of life/death for patients and families

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

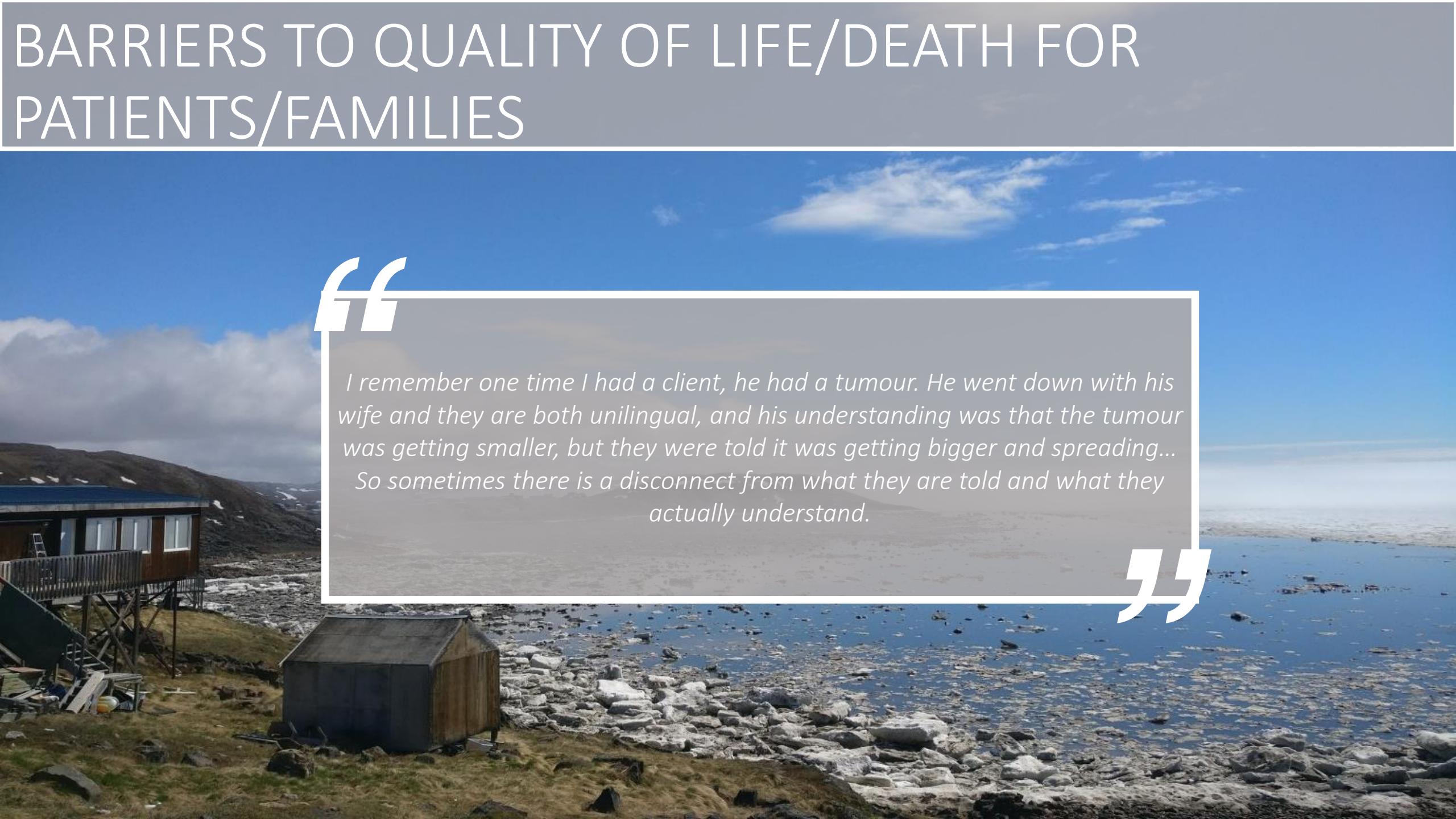


Religion/spirituality

Involvement & role of the family

Home care program

BARRIERS TO QUALITY OF LIFE/DEATH FOR PATIENTS/FAMILIES



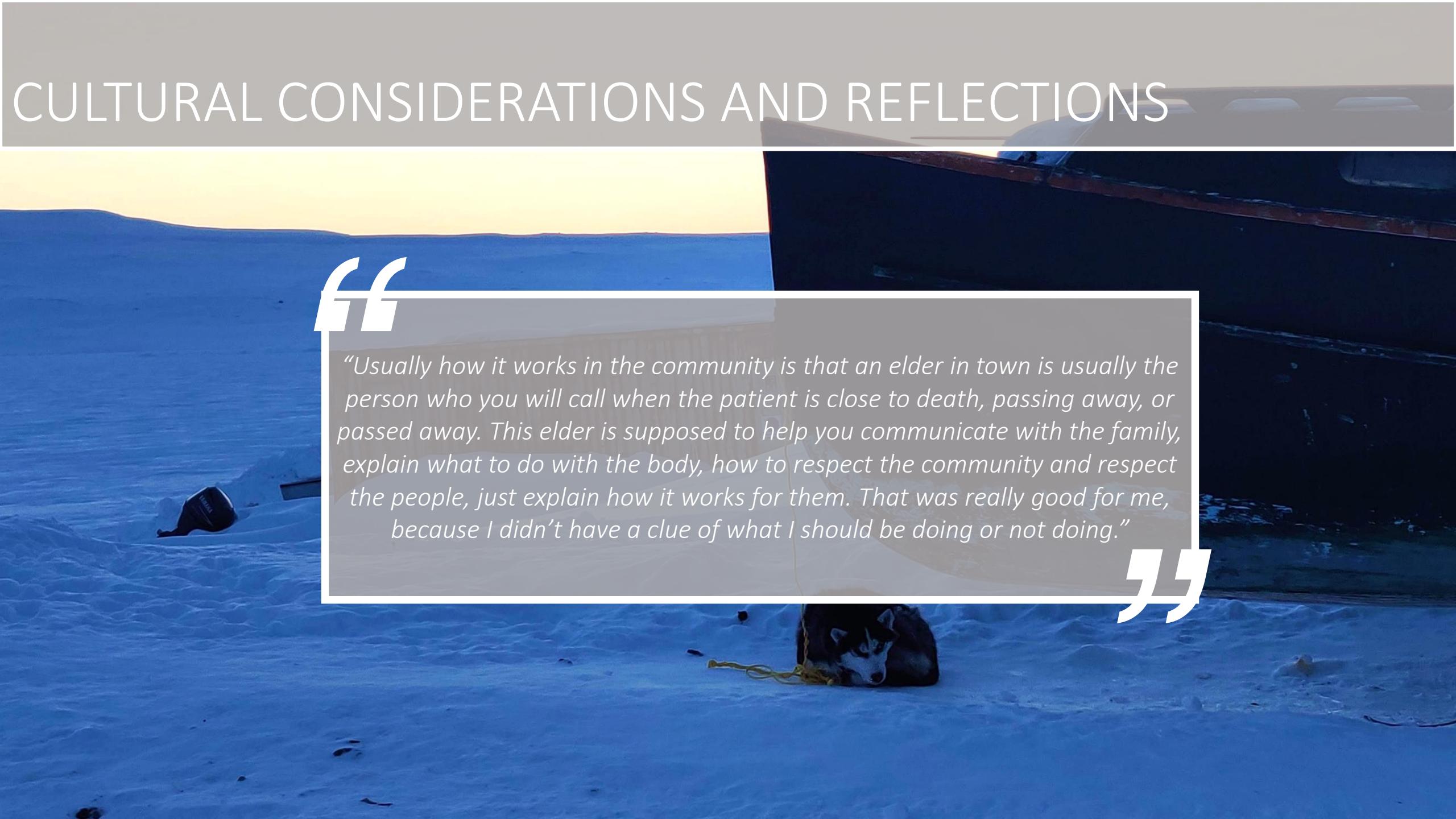
I remember one time I had a client, he had a tumour. He went down with his wife and they are both unilingual, and his understanding was that the tumour was getting smaller, but they were told it was getting bigger and spreading... So sometimes there is a disconnect from what they are told and what they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

DIFFICULTIES PROVIDING CARE FOR HEALTH CARE PROFESSIONALS



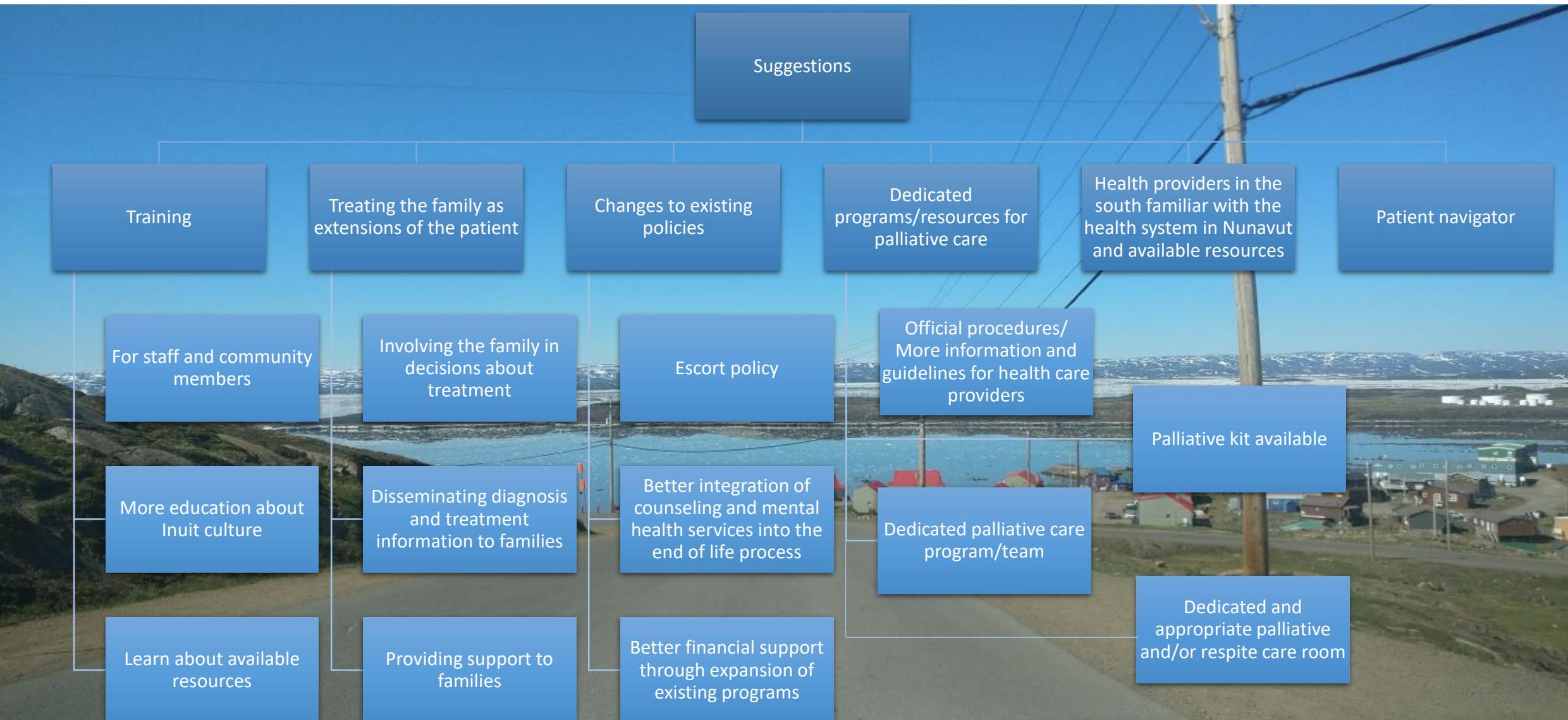
It brings sadness, because you know you're going to bring bad news to the family, but at the same time, you also... feel like you want to provide as much support as you can provide. Overall, to me though, it's sadness. I've had situations where I've cried and cried with the family, because these are 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



Training

Specific training programs in cancer care, palliative care, and counseling for staff and community members

More education about Inuit culture

More support for family caretakers

Treating the family as an extension of the patient



A landscape photograph of a coastal town. In the foreground, there's a dirt road leading towards a cluster of colorful houses with red roofs. Beyond the town, a wide body of water stretches to a range of mountains under a clear blue sky.

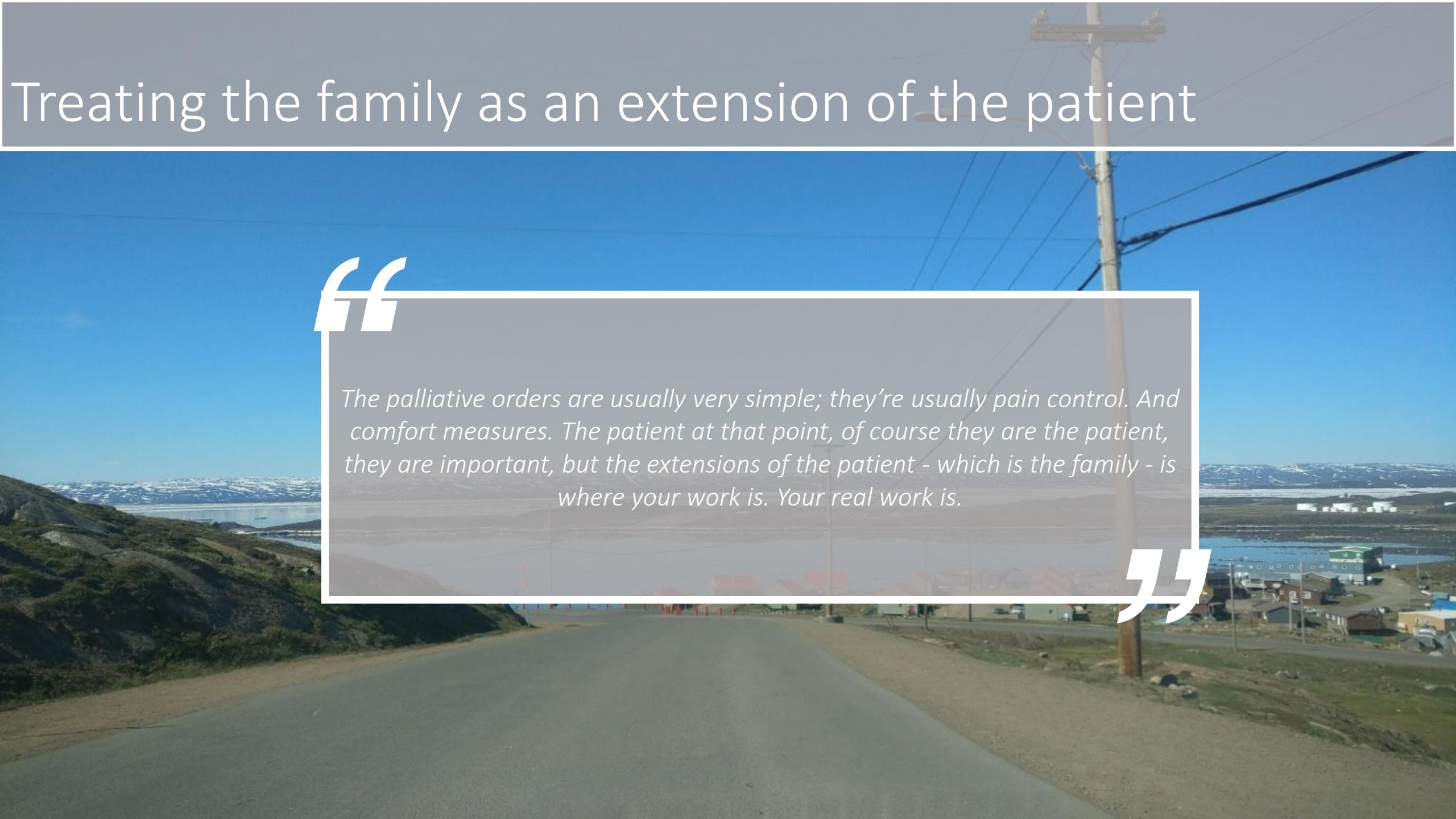
Treating the family as an extension of the patient

Involving family in decisions about treatment

Disseminating diagnosis and treatment information to families

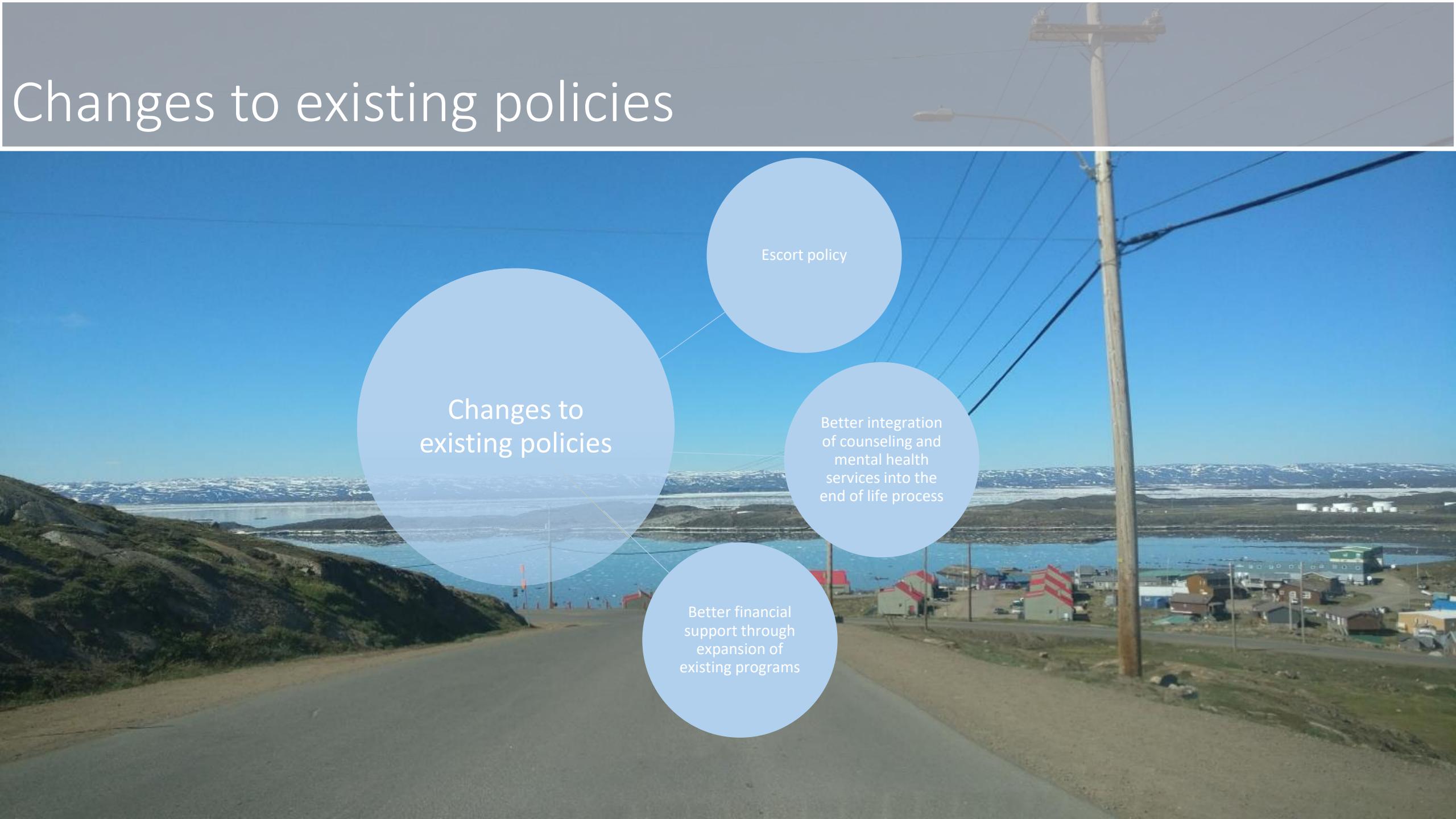
Providing support to families

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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