Nova Scotia Hospice Palliative Care Association

May 8 2025

CONFERENCE SUMMARY: THE CULTURAL IMPLICATIONS OF DEATH, DYING, AND GRIEF

Pjila'si' and Indigenous Welcome:
Angela Doyle Faulkner

"Truth and Reconciliation is not a destination but rather a lifelong journey"

The NSHPCA 2025 Conference brought together professionals, researchers, and community leaders to explore the profound impact of culture on death, dying, and grief. This year's theme, ***Cultural Implications of Death, Dying, and Grief****, focused on fostering understanding and dialogue about the diverse ways cultures navigate end-of-life experiences.*

Healing Pathways
WITH NSHPCA

Over the past decade, the Nova Scotia Hospice Palliative Care Association (NSHPCA) has broadened its work to raise awareness and understanding of grief. Today, NSHCPA works through Healing Pathways to help fund community-based initiatives supporting people in grief and emotional wellness. **Click the photo** for a link to the Healing Pathways Page!

Summary Provided By Clinical Nurse Educators for Palliative Care, May 2025

Dr. Amit Arya - Keynote Speaker

Equity at the Heart of Care: Integrating Cultural Safety and Anti-Racism in Seniors and Palliative Care while supporting Grief and Bereavement

- Racism is a **Public Health Crisis**
- Racism in Canada is not just a historical issue; it does exist and it shapes the care people receive in our healthcare system.
- It's important to confront uncomfortable truths about how our healthcare system is built on systemic inequities and racism: examples to look up include the testing of "Pablum", the history of Sickle Cell disease research and treatment, and how COVID-19 disproportionally impacted minority groups.
- We need to focus on creating "Safer" spaces rather than completely "safe" spaces.

> "Racialized Communities are at higher risk of experiencing inequitable healthcare from the moment of birth through life, extending into end-of-life"

Take the Implicit Bias Test from Harvard University: Click Here

Implicit Bias

- Culturally pervasive, affects everyone.
- Can significantly affect health outcomes and diagnoses (e.g., symptom dismissal, longer diagnosis times)

Structural Racism

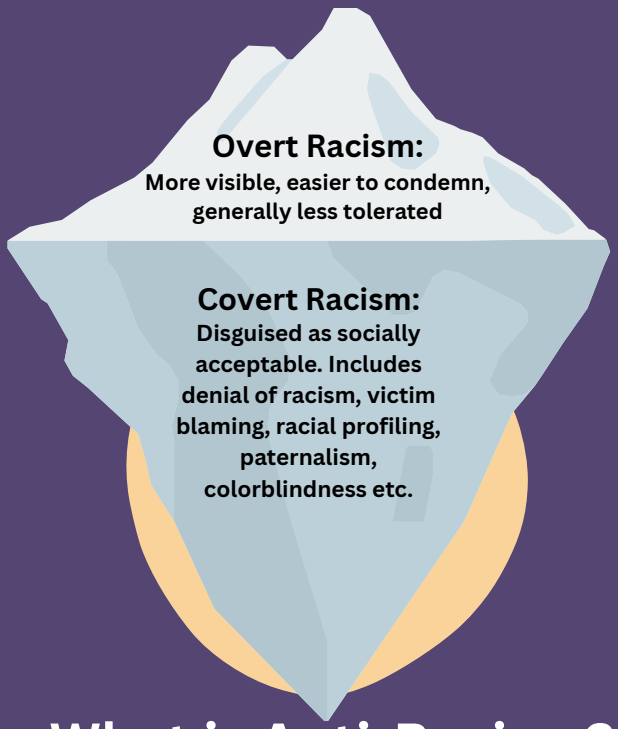
- Insidious, normalization of historical dynamics that uphold white supremacy
- Permeates every piece of society
- Deeply ingrained, it's the most pervasive form of racism.
- When the power dynamic favors those who are able to uphold racial prejudice in the structure of our society and public services.

Race Vs. Racism

- Race isn't a determinant of healthcare outcomes; racism ***IS***. Factors that determine how different races are impacted by disease are not rooted in the **race** of the person, but rather how **racism** has impacted the healthcare system.

What is Racism?

Racism = Racial Prejudice + Power



What is Anti-Racism?

"An active process and responsibility of identifying, challenging and eliminating racist policies, structures, practices and attitudes" Anti-racism is not a passive stance. We need to urgently address systemic racism as it is actively harming people trying to access healthcare.

Dr. Amit Arya - Keynote Speaker

How does Racism impact Palliative Care?

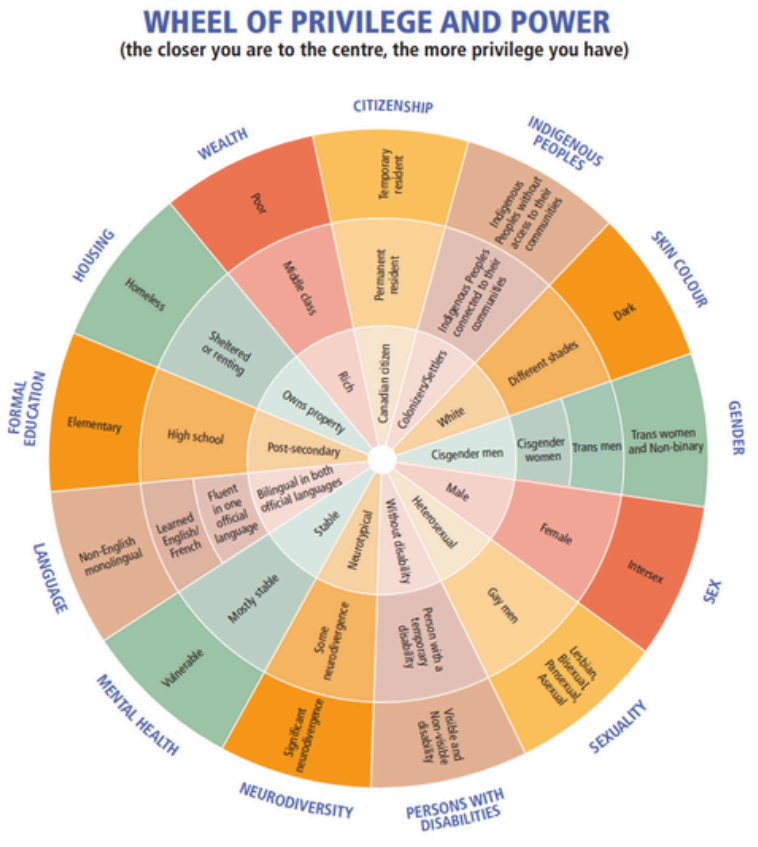
- Language barriers
- Request for non-disclosure (is culturally important for some, which is in direct opposition to western medicine philosophies)
- Collective decision-making (western medicine emphasizes individual decision making / SDM control)
- Religious and cultural beliefs
- Mistrust of western medicine
- Less access to palliative care

- We need to work hard to build trust with racialized communities, before they access palliative services if possible.
- Language concordant care ***improves*** health outcomes. Make sure we are accessing interpreters and culturally appropriate language tools
- NSH Language tools: Language Services Sharepoint site

Privilege and Intersectionality

Privilege in one area of our lives doesn't remove discrimination in other areas. Using an intersectional approach tells us that humans are multifaceted and have different privileges and disadvantages.

How are seniors affected by racism? Increased rates of poverty, more housing insecurity, decreased access to culturally appropriate LTC homes , lower standards of care (as evidenced by COVID-19 response).



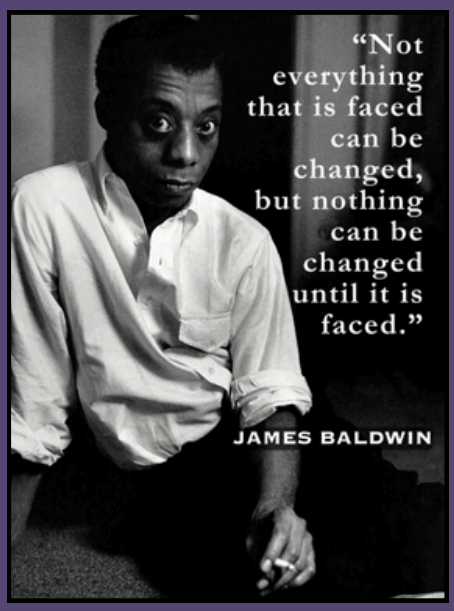
https://www.canada.ca/en/immigration-refugees-citizenship/corporate/mandate/anti-racism-strategy/change.html

"Sometimes Inequity isn't visible until people share their stories and situations"

How can we turn awareness into action?

1. ***Treat people differently according to their needs:*** Applying an "Equity" lens to patient care means understanding and responding to individual needs. Some people require additional support and resources, not to have an advantage, but to simply level the playing field.

2. ***STOP:*** tolerating injustice
SPEAK: out against forms of discrimination
USE: your privilege to voice support



3. ***REINFORCE:*** a trauma informed approach
REFRAME: the "difficult" patient
DEVELOP: a trauma informed road map

4. ***Learn by centering marginalized voices:*** integrate perspectives of patients and caregivers with lived experiences of racism and discrimination

5. ***Assess and measure systemic change:*** collect equity informed data, examine all systemic institutional policies, review hiring and training processes.

> We must stay the course on Health Equity!
>
> It's not political, it's ethical. Healthcare is a right not a privilege.
>
> This work is not optional!

6. ***Improve access and create inclusive spaces:*** how are we accommodating specific needs of racialized people (professional interpretation services, spaces for cultural or spiritual practices)

7. ***De-centralize power for community led solutions:*** give voice back to marginalized communities, harness social and financial capital to decentralize power, enable community led trauma informed approaches that address disparities.

@AmitAryaMD

"This is a lifelong process that demands consistent effort, commitment, funding, prioritization, and leadership. Think of it like a quality improvement initiative"

Colleen Belle

Intercultural Competence and How Best to Support Newcomer Immigrants through Grief and Bereavement

Imagine how you might feel …

if your whole world was falling apart while you and your family were resettling in a completely new environment, and you were very dependent on a system and individuals that were not aware, understood, or shared your cultural views.

isans | Immigrant Services Association of Nova Scotia

A) Always center the impacted
L) Listen and learn from those experiencing oppression
L) Leverage your privilege
Y) Yield the floor

Acronym shared by Senator Wanda Thomas Bernard

Nova Scotian Immigrant Voices:

- First-voice 'S' from India: Culturally diverse with Christianity, Islam, Hinduism influence the traditions and rituals e how the body is treated, who should visit, beliefs in what happens to the soul afterwards. Christians invite a priest or pastor to pray with their loved one before as they approach death.
- First-voice 'M' from Syria: For Muslims preparation for death is very important with declaration of faith being the final words. In Islam body must be buried very quickly, ideally within 24 hrs, and cremation not permitted.
- First-voice "A' from Arabia: Islam strong religious, social, and traditional customs. In some death is seen as a test that patience and faith is emphasized, and excessive wailing is prohibited. the dying person is encouraged to recite their declaration of faith or have someone nearby to do it for them. In Arab culture it is common to distribute charity in the deceased's name, and is some instances remember the deceased on the 40th day.
- First-voice 'S' from Iran: cultural and religious beliefs often emphasize modesty and restraint, with the hope of experiencing greater rewards in the afterlife, with the hope of experiencing greater rewards in the afterlife. This perspective can lead to a profound sense of sadness surrounding death, as both the dying individual and their family may feel that life was not fully experienced.
- First-voice 'M' from the Caribbean having many family members visit regularly and pray with the loved one as they approach death.
- First-voice "P' from the USA: death in the US has become far more of a medical event than a communal or religious one. often framed as a traumatic or at least a Significant event, and better not to include the children. "Death anxiety" is typically experienced more by those who have less experience with it. Dying with dignity takes many forms and has experienced a resurgence, such as with living wills and related legal instruments.
- First-voice 'S' from India. Hindu death rituals, the body must remain at home until cremation which usually happens within 24 hours of death.

"We need to find what is meaningful and supportive to individuals, and not be prescriptive with our approach to grief and bereavement"

"Nothing about you - without you"

How do we build Intercultural Competence?

- Practice patience and empathy
- Avoid stereotyping, considering them as tendencies rather than absolutes
- A translator or interpreter would be an asset if English is not their first language
- Connect them with relevant departments or offices where next steps, as they will not be familiar with after death processes in Nova Scotia
- "Ask the bereaved person and their family how you can help them to address their cultural and spiritual needs and help with practicalities, such as registering the death."
- Seek advice from their community leaders about how you could be more supportive
- Identify, prevent, and remove existing barriers
- Provide equitable opportunities, participating in planning
- Hear stories, don't make assumptions
- Be open to different perspectives
- Embrace individuals regardless of demographic make up.

Lana MacLean

Are there Health disparities in End of Life? Consider African NS Lens

Study by John's Hopkins (2020): Black patients voluntarily seek substantially more intensive treatment, such as mechanical ventilation, gastronomy tube insertion, hemodialysis, CPR and multiple emergency room visits in the last six months of life, while white patients more often choose hospice service.

Why might this be?

- Cultural importance of "did we do everything we could, did we do enough for our loved one" leading to more invasive treatment decisions. The concept of "fighting the good fight" lends the ANS population to see palliative care as "giving up".
- The African American /ANS community has historically been reluctant to use hospice services. Experts say mistrust of the medical profession and a lack of knowledge about hospice organizations are two of the reasons.

Being uncomfortable means you're willing to grow. Be uncomfortable and also have the intention to learn and do better, don't be uncomfortable and practice avoidance.

"Cultural Competence is about you doing the best you have with the skills you have. Don't get stuck on the race thing; connect with people from a relationship lens"

Literature supports the position that matters of race, ethnicity, and cultural congruence are less important than more individual, interpersonal caregiver traits such as **genuineness, warmth, acceptance, and empathy**, which are crucial to establishing a bond and meaningful rapport with patients at the end of their lives.

Most important, on this view, is the caregivers' willingness to become acquainted with aspects of their patients' culture, social class, and spirituality as they affect attitudes, beliefs, values, and traditions about death and dying.

Working with people means working with their families, and with ANS' this also means working with communities. Organizations need to reach out to black communities through their churches, barber shops, hair salons, community groups etc. to encourage the palliative approach to care.

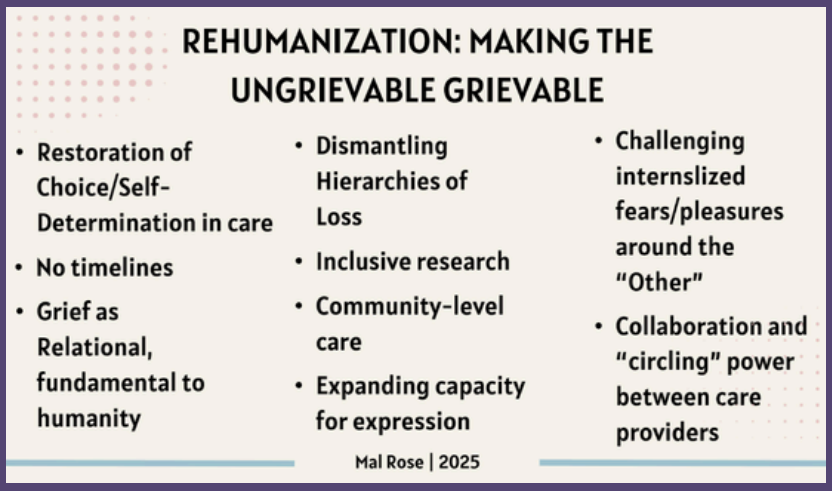
The "Trifecta" of ANS Assessment

Mal Rose

Grieving While "Ungrievable": 2SLGBTQIA+ Grief in a hostile world.

"If you want a group of people ungrievable the first strategy is to simply not report their deaths...a second technique might be to portray the target population as kind of dead already."

"An example might be the portrayal of indigenous people as quasi extinct or relics of a dying era or portraying old people and disabled people as half dead already. Queer people too are portrayed as courting death through risky lifestyles. The common thread is that death is assumed to have pretty much already happened so why grieve the forgone conclusion...."

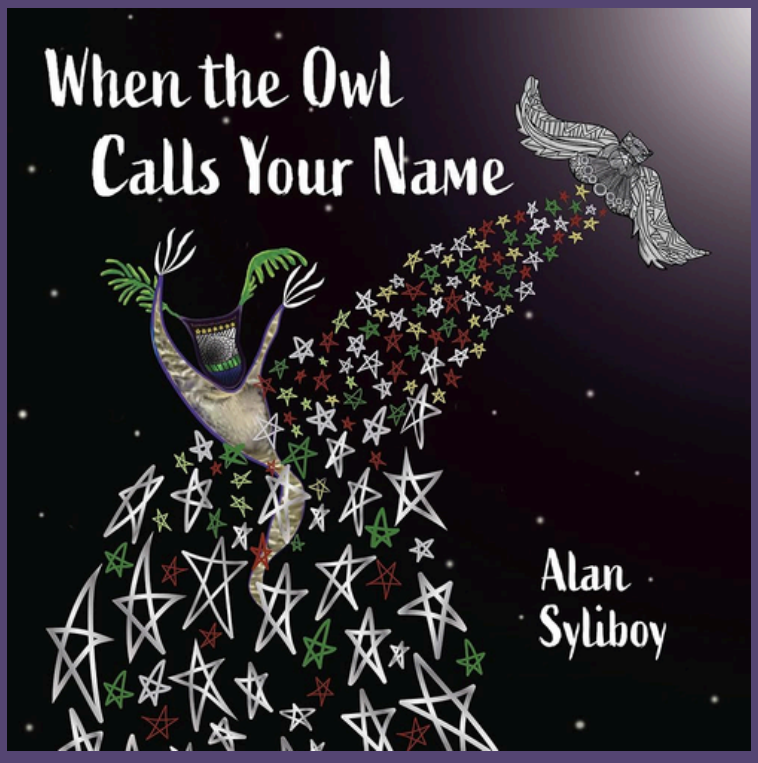


If you've ever thought to yourself "I don't know anything about Queer Grief", a bridge to understanding is to center the conversation around "ungrievable" grief, and reflect on situations you may have felt you were not "allowed" to fully grieve. Examples from the audience were grieving pets, grieving a miscarriage, grieving after leaving a bad marriage, and more.

Alan Syliboy

When the Owl Calls Your Name

Exploring Mi'kmaw spirituality, life and death.



"Ceremony is Important, it helps us make sense of loss"

In our sweat lodges, you go to pray for others not for yourself. It's a communal process of prayer, a place to process grief and a place to support each other"

"A community is a healthy, good, community when someone's time comes and everyone shows up. When a funeral occurs, we come together. There's community intimacy"

"People have a lot of fear of [death], I think if they come to see that it is part of nature, then they would be less afraid of it"