“Don’t Tell Mom!” Developing Cultural Competency in Goals of Care Discussions

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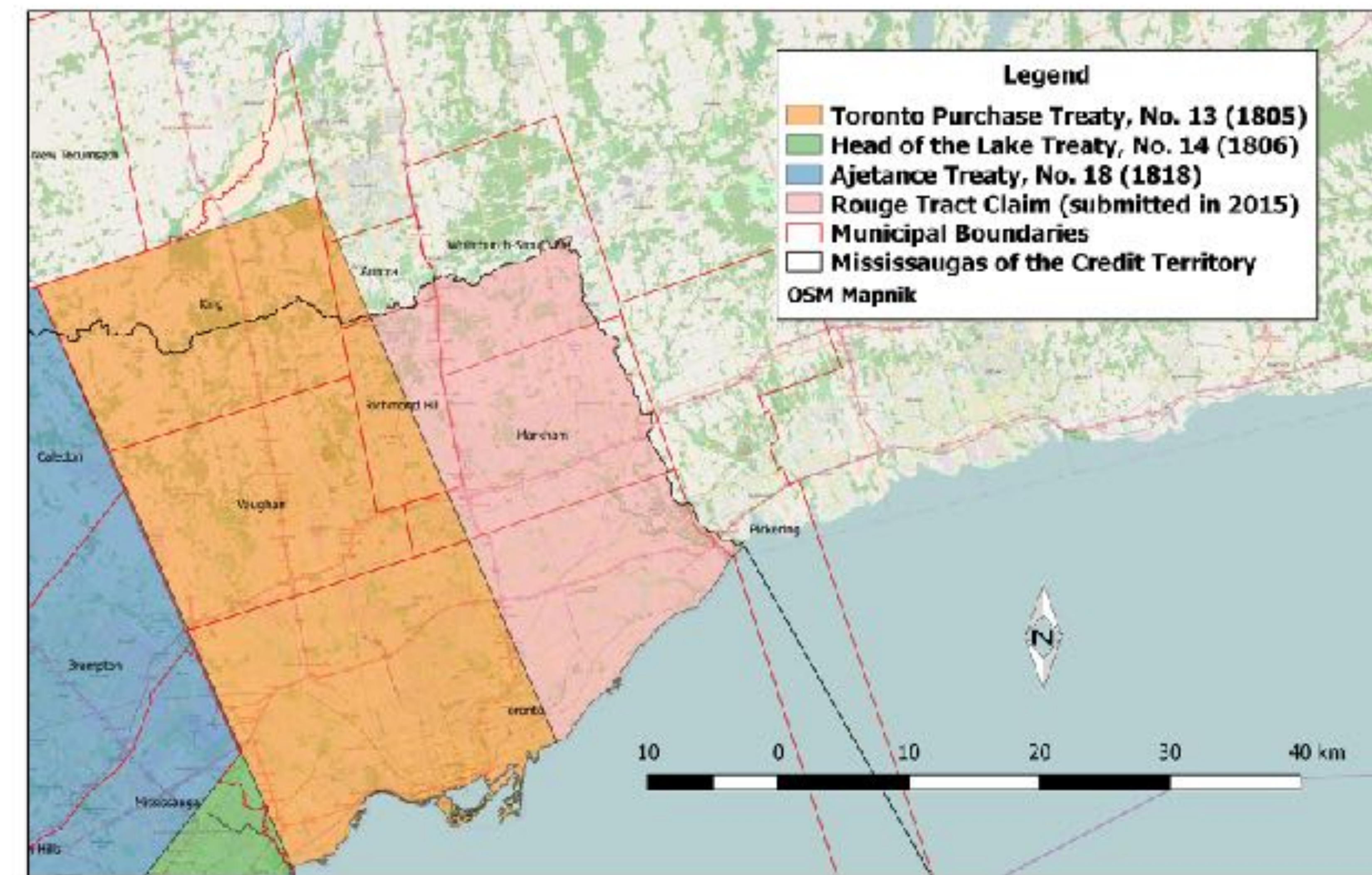
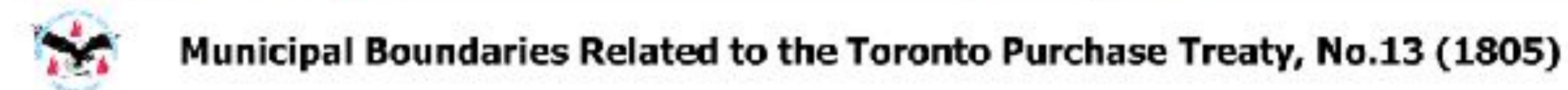
October 16, 2020

Land Acknowledgement




Municipal Boundaries Related to the Toronto Purchase Treaty, No.13 (1805)

Ancestral Traditional Territories of the Ojibway, the Anishnabe, and the Mississauga's of the New Credit whose territory we are gathering on today. This territory is covered by the Upper Canada Treaties.

Native-Land.ca

Presenter Disclosure

- Presenter: Dr. Amit Arya
- Relationships with commercial interest:
  - grants/research support: nil
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  - Consulting fees: nil
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Presenter Disclosure

- Presenter: Dr. John Davey
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- **This program has received no financial or in-kind support from any third party organization**
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  - **Nil.**

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Mitigating Potential Bias

- Not applicable

Objectives

- understand some of the inequities which exist in racialized communities in access to & provision of palliative care in LTC
- understand cultural and religious values and how they may have a large impact on end-of-life decision making
- understand “futility” in medical ethics and the difficulties in applying this principle to patient care
- develop communication strategies which promote collaborative decision making and decrease bias

Racial Disparities in Palliative Care

JAMA | Original Investigation | CARING FOR THE CRITICALLY ILL PATIENT

Association Between Immigrant Status and End-of-Life Care in Ontario, Canada

Christopher J. Yarnell, MD; Longdi Fu, MSc; Doug Manuel, MD, MSc; Peter Tanuseputro, MD, MHSc; Therese Stukel, PhD; Ruxandra Pinto, PhD; Damon C. Scales, MD, PhD; Andreas Laupacis, MD, MSc; Robert A. Fowler, MDCM, MS(Epi)

Racial Disparities in Palliative Care

Figure 2. Proportion of Decedents Dying in Intensive Care: Recent Immigrant Characteristics[a]

	No. (%) Dying in Intensive Care		Unadjusted Relative Risk[a] (95% CI)
	Long-standing Resident	Recent Immigrant	
Region of Birth			
Northern and Western Europe		221 (8)	0.84 (0.74-0.95)
Northern America		121 (11)	1.11 (0.94-1.31)
Southern Europe		225 (11)	1.11 (0.98-1.26)
Eastern Europe		873 (13)	1.26 (1.19-1.35)
East Asia		1118 (14)	1.38 (1.31-1.46)
Oceania		59 (15)	1.46 (1.15-1.85)
Central America, Caribbean, and Mexico		611 (16)	1.59 (1.48-1.71)
South America		431 (17)	1.67 (1.53-1.82)
Southeast Asia		776 (17)	1.74 (1.63-1.85)
Western and Central Asia		597 (18)	1.78 (1.66-1.92)
Africa		482 (18)	1.84 (1.70-2.00)
South Asia		1893 (20)	1.96 (1.89-2.05)
Time in Ontario, y			
21-30		1826 (14)	1.42 (1.36-1.48)
16-20		2039 (15)	1.52 (1.46-1.58)
11-15		1631 (16)	1.56 (1.49-1.63)
6-10		1152 (17)	1.72 (1.63-1.81)
3-5		545 (18)	1.75 (1.62-1.89)
≤2		217 (20)	2.03 (1.80-2.29)

Racial Disparities in Palliative Care

- African Americans noted to resist the concept of hospice
- Much more likely to receive aggressive care
- half of white Medicare beneficiaries enrolled in hospice, less than a third of blacks
- for those > 70 years, about 40% of whites have advanced directives, only about 16% of blacks

Varney, 2015

Racism in Palliative Care

- ***"likely representative of a health disparity rather than a difference in preference for more aggressive EOL care"***
- ***"disparities in communication may be a major underlying factor driving differences in care"***

Shen et. al., 2019
Mack et. al., 2010

Perceptions of palliative care in a South Asian community: findings from an observational study

Naheed Dosani, Ravi Bhargava, Amit Arya, Celeste Pang, Pavinder Tut, Achal Sharma & Martin Chasen

BMC Palliative Care **19**, Article number: 141 (2020) | Cite this article

511 Accesses | **1** Altmetric | Metrics

Recent immigrants in Ontario wait longer for admission to long-term care facilities

Wait times ranged from 39 to 137 days more than for longstanding residents.

Researchers tracked Ontario residents aged 65 or older who were placed on the long-term care waitlist between 2007 and 2010. Recent immigrants (those granted permanent residency or citizenship after 1985) were compared with long-standing residents by demographic, functional health and caregiver characteristics.

Compared to long-standing residents, recent immigrants waiting for long-term care were more likely to:

- Be slightly younger
- Live in lower-income neighbourhoods
- Have fewer comorbidities but poorer functional status

Caregivers of recent immigrants were more likely to:

- Report burnout (**26.9%** vs. **20.7%**)
- Report inability to continue providing care (**21.6%** vs. **16.7%**)
- Live with a recent immigrant (**60.6%** vs. **39.7%**)
- Be the children of recent immigrants (**68.0%** vs. **55.2%**)

Qureshi et al., *JAMDA*, 2020.

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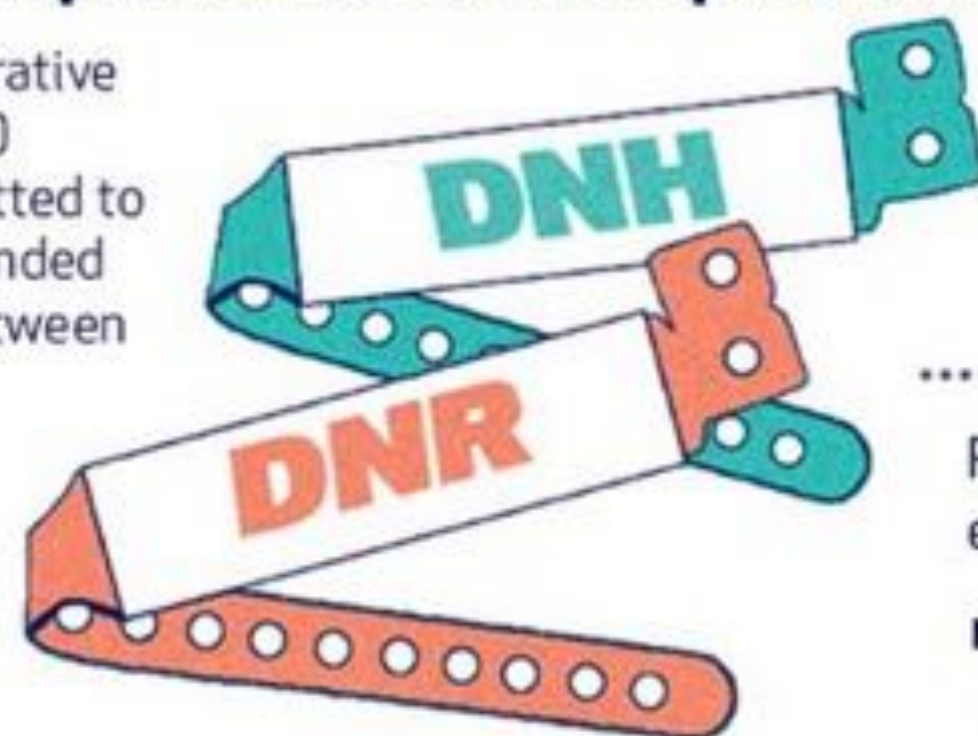
Ontario nursing home DNR and DNH orders reduce inappropriate hospitalizations, but not entirely

Do-not-resuscitate (DNR) and do-not-hospitalize (DNH) orders lowered, but did not eliminate, risk of hospitalization or in-hospital deaths, suggesting room for improvement.

Study looked at administrative records for nearly 50,000 residents who were admitted to Ontario's 640 publicly-funded long-term care homes between 2010 and 2012.



3 in 5 nursing home residents had a DNR recorded at admission

1 in 7 had a DNH

Residents with a DNR or DNH were less likely to experience **hospitalization or in-hospital death**:

HOSPITALIZATION:

DNR: 13% less likely / **DNH: 30%** less likely

IN-HOSPITAL DEATH:

DNR: 40% less likely / **DNH: 60%** less likely

The authors say these findings indicate that DNR and DNH orders do not prevent all potentially avoidable hospitalizations or in-hospital deaths. They recommend better communication, along with additional supports to keep residents in their homes.

Tanuseputro P. et al. *J Am Med Dir Assoc.* 2019.

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The Ottawa Hospital | L'Hôpital d'Ottawa

Racial Gaps in Palliative Care in LTC

- DNR/DNH much more likely if LTC resident spoke English/French
- culture, race & ethnicity are important factors in resident & family decisions

Tanuseputro et. al., 2019

Racial Gaps in Palliative Care in LTC

Language group	DNR	DNH
East Asian	455 (51.1)	41 (4.6)
English	25,502 (62.6)	6388 (15.7)
European	1859 (48.1)	419 (10.8)
French	1006 (63.2)	189 (11.9)
Other	933 (54.2)	219 (12.7)
South, Central, and Western Asian	245 (39.7)	39 (6.3)

Tanuseputro et. al., 2019

Racial Gaps in Palliative Care in LTC

Palliative care measure	Whites ($n = 862$)	Minorities ($n = 262$)	p value
Advance care planning, % of residents with			
Do-not-resuscitate orders	69.5	37.3	<.001
Living wills	39.0	5.0	<.001
Health care proxies	36.2	11.8	<.001
Documentation of in-depth discussion	7.3	6.5	.738

"racial minorities disadvantaged when compared to their fellow white residents"

Reynolds, 2008

Cultural Safety

“An 87 year old Chinese woman, who was dying of lung cancer, was served a pureed nacho casserole 4 days before she died”

Cultural Safety

- Cannot speak language
- Cannot communicate about health concerns
- Cannot engage in religious practices
- Do not want to eat unfamiliar food
- Cannot practice traditions/celebrations

Cultural Safety

Colonialism,
Capitalism &
Oppression

graphic by Dr. Nanky Rai

Cultural safety

- Racism in health care can occur at three levels:
  - Interpersonal- interactions between individuals
  - Systemic- production, control & access to resources in a society
  - Internalized- incorporation of racist attitudes, beliefs or ideologies into one's worldview

Cultural Safety

Let this be our united pursuit

» Name it!

» Do it….boldly!

» Be Better!

“ABCDE Tool”

- Attitudes — disclosing prognosis, discussion of death/dying
- Beliefs — spiritual beliefs, meaning of death, miracles
- Context — historical & political context of their lives
- Decision-making — patient centred or family/community centred
- Environment — available resources- family, neighbourhood

Kawaga-Singer, M. et. al., 2001

Decision Making Across Cultures

Non-Disclosure

Collective Decision Making

Futility

Non-Disclosure

- 85 year old South Asian gentleman with advanced CHF with severe aortic stenosis, frailty, mild dementia
- daughter very insistent that father is not told about the illness as he will “give up and die earlier”
- daughter continues to tell father: “you will get better soon with hospital treatments”

Non-disclosure

- Lung cancer= “illness involving the lungs”
- Lung cancer metastatic to brain= “illness of the brain”
- Chemotherapy= “you don’t have cancer yet, but if you are not treated, it may progress to a cancer"

Mizuno et. al. 2002

Non-disclosure

- may be viewed as serious or impolite
- may provoke unnecessary depression or anxiety
- may eliminate hope
- speaking aloud about illness or death, even hypothetically, may make situation real because of the power of spoken word

Searight et. al., 2005

Non-disclosure

- use another person's EOL care experience as an example
- frame the discussion as a standard question by policy
- acknowledge cultural taboos and ask for consent
- provide a longevity statement as a prompt or describe a longevity scenario
- Work together to brainstorm and negotiate solutions

Chi et. al., 2018

Collective Decision Making

- A 79 year old Arabic-speaking lady with advanced pulmonary fibrosis and renal failure; worsening breathlessness and O2 requirements
- Case conference with daughter (POA) to discuss symptom management and EOL concerns:
  - “I need to speak to other family members before agreeing to your suggestions”
  - “In our culture, people always talk to the *family* about serious matters”

Ruhnke, et. al. 2000

Collective Decision Making

- “patient centred" decision making is not universal!
- patient autonomy favoured in US, family-centric approach in Japan
- Decision making may be a “family duty”

Ruhnke, et. al. 2000

Collective Decision Making

- “would you be more comfortable if I spoke with your (son, daughter, brother) alone, or would you like to be present?”

- “do you prefer to make medical decisions about future tests or treatments for yourself, or would you prefer that someone else make them for you?”

Searight et. al., 2005

Futility

96 year old African Canadian gentleman with advanced dementia- has 5 children including 2 who are nurses

Children insistent their father “be kept alive forever,” want him to receive CPR and all life-prolonging measures

Children often come to pray next to their father; patient has multiple visitors from members of the church

Sokol, 2009

Futility

no specific definition, several subtypes:

- Physiologic Futility: an intervention that is incapable of achieving the stated aim/goal
- Quantitative Futility: when the likelihood or chance that a treatment will benefit a patient is exceedingly low
- Qualitative Futility: when the quality of benefit is felt to be exceedingly low or to be outweighed by the costs

Sokol, 2009

Futility

Filial Piety

- children to fight with all their strength to serve and "save" parents, regardless of the cost
- fear of societal shame

Zhang et. al., 2015

Futility

Printed from
THE TIMES OF INDIA

Right to live includes right to die: Supreme Court

TNN | Mar 10, 2018, 02:19 AM IST

PAVES WAY FOR DECRIMINALISING SUICIDE

Matter Of Life & Privacy: The judgment paves the way for decriminalising suicide by suggesting that the right to die should now be considered a part of right to life and right to privacy. Cites Mental Healthcare Act, 2017, as the first step

State's Failure: "When the state is not being able to guarantee the right to healthcare for all, can the citizens be denied the right to die with dignity?" asks SC

Stressed Finances And Facilities: Poor are forced to sell properties and endanger family's future

to treat terminal cases. SC also questions the fairness of limited life-saving facilities being blocked by patients who won't recover

Euthanasia Was In Practice: Buddhism and Jainism allow euthanasia, while Hinduism, Islam and Christianity are against it. SC found that limited euthanasia was allowed through medical council regulations, 2002

The Safeguards: Mandatory provision for a double medical board, involving judicial magistrate or collector or high court, to implement euthanasia and living will

What About Active Euthanasia? Allowed in several western countries, active euthanasia, or assisted suicide, will continue to be a crime and can be made legal only through legislative action

Rote hue aate hain sab, hansta hua jo jayega, woh muqaddar ka sikandar, janeman kehlayega

(title song of 1978's Bollywood superhit quoted by **Supreme Court**)

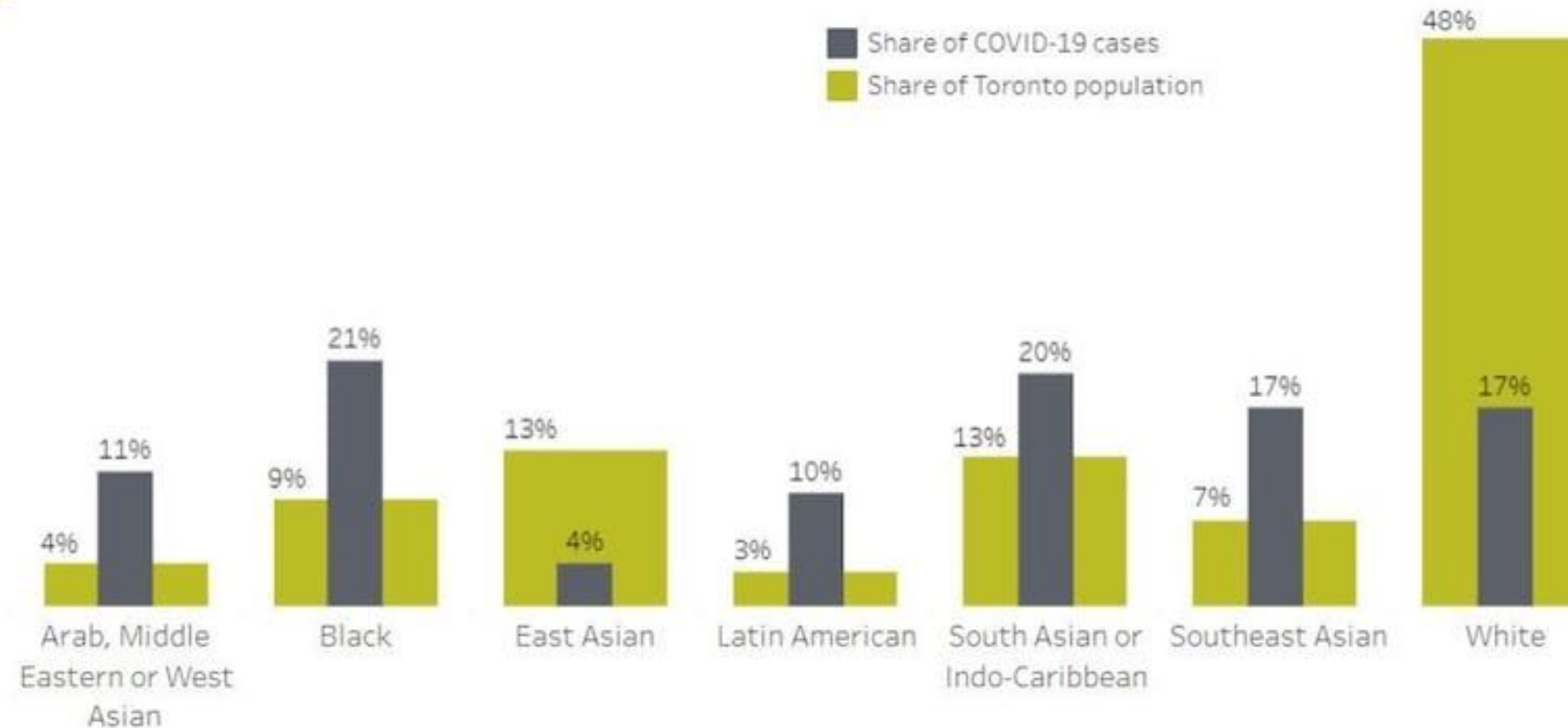
Futility

- family members may live for years with psychological after-effects & regrets of EOL decisions
- is there a point where a patient "could be beyond suffering," yet needs of caregiver are clinically & ethically significant?
- could performing futile treatments show that we care about families & respect their individual needs?

Troug, 2010

- What do you understand about what's going on with ____?
- What are you hoping we can achieve for ____?
- If ____ could tell us, what do you think ____ would want to achieve?
- Of those things, what would be the most important?
- In what situations, if any, could you imagine ____ no longer wanting to live?
- Do you have any concerns about the care ____ is getting?
- Are there disagreements among family members?

A pandemic of racism



Omo Shèpètérì
@ItsMissIsi

They just called me for a Nigerian COVID patient they want to extubate but weren't sure if he didn't understand English or was just agitated/delirious. I walked in the room and greeted him in Yoruba. He stopped fidgeting and looked at me, his eyes lit up and he started crying

4:52 PM · 2020-04-23 · Twitter for iPhone

3,385 Retweets **16K** Likes

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Seema Marwaha @SeemaMar... · 12h

I saw a #covid19 + patient who was very ill and only speaks Portuguese. I 3-way called language line, my cell and the phone in his iso room. All he would say was that he was scared and alone. He has no family. His code status was discussed with him in this manner. #thissucks

1 3 12

Summary

- Racial gaps in care exist throughout healthcare, including in palliative care and LTC
- many LTC patients or their family members speak primary language other than English
- some cultures view directly informing patients of diagnosis as harmful

Summary

- treatment decisions may be made by a family-wide consensus or physician-family collaboration
- patients in some cultures, particularly those with a history of health care discrimination, may not trust physicians who are of a different ethnic background

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OUR MISSION

INNOVATIVE HEALTH CARE DELIVERED WITH COMPASSION

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GOING BEYOND

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