Restricted visiting in care settings during CoVID-19: Well-intentioned, but Should Resulting Harm be Minimized? An Ethics View

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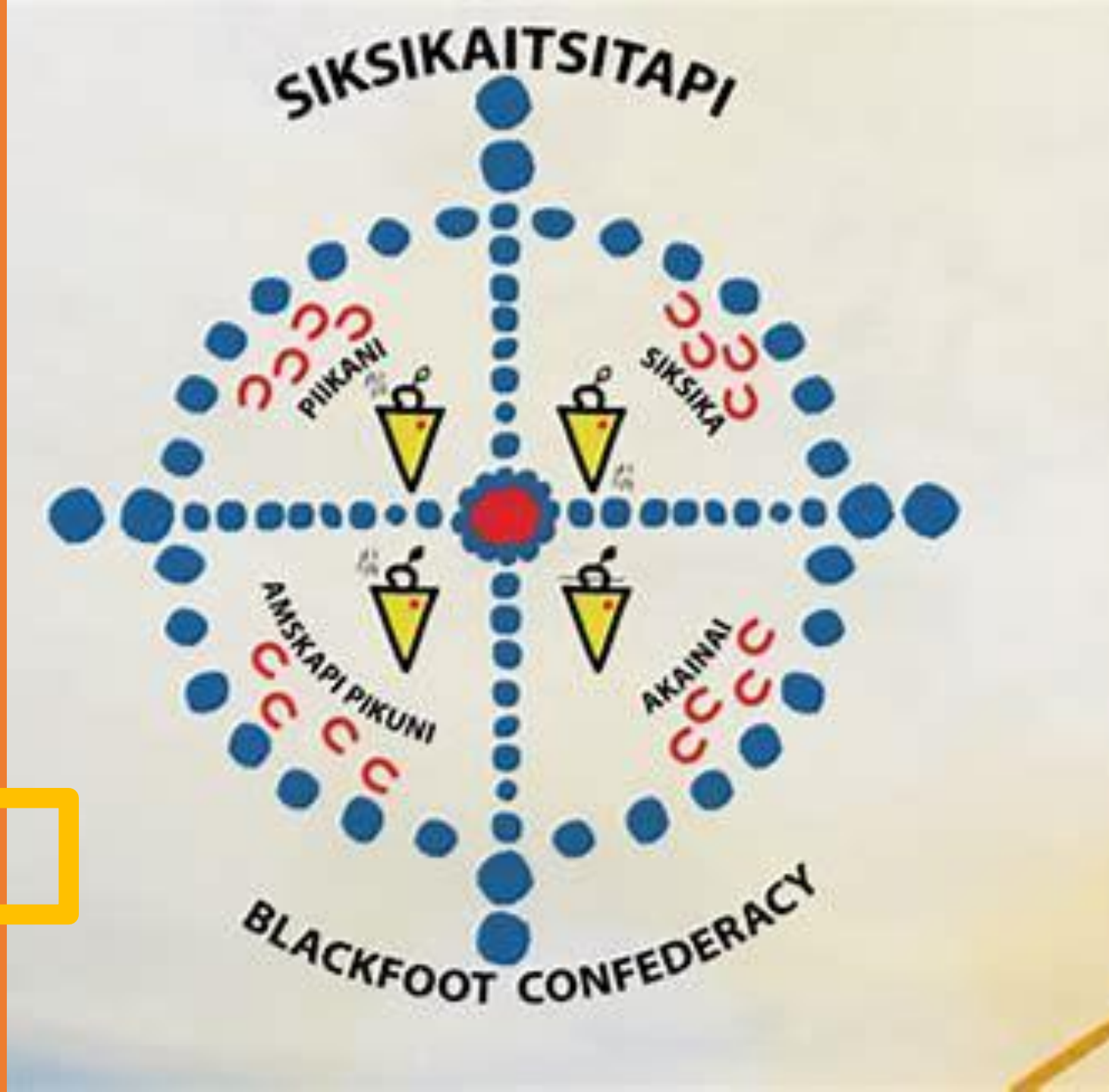
- Via Zoom webinar

Land Acknowledgement and Commitment

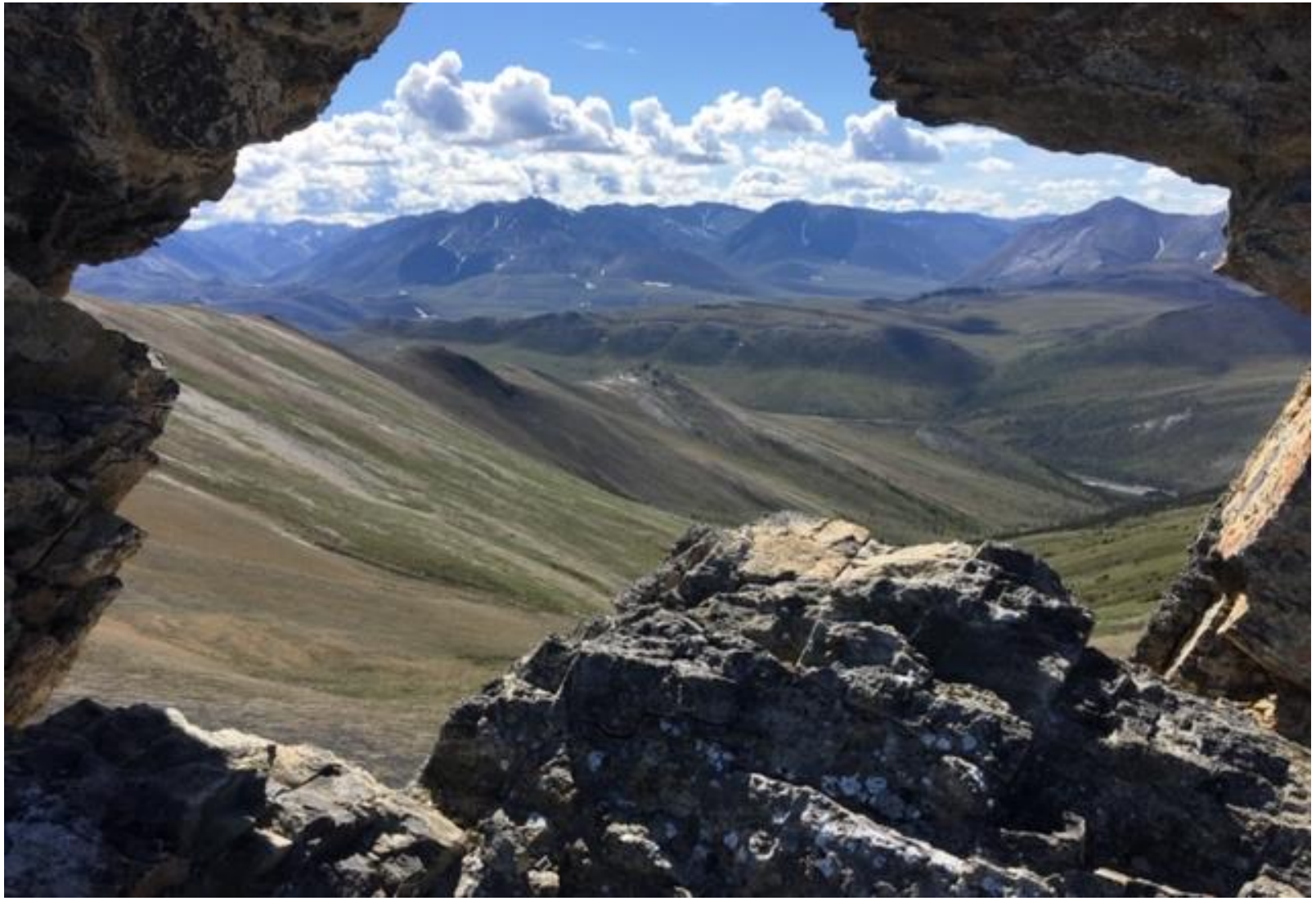


Declarations

- No Conflicts to Declare
- I have taken a strong advocacy position about today's topic
- Affiliations:
  - Associate Clinical Professor, University of Alberta, John Dossetor Health Ethics Centre
  - Clinical Associate Professor, University of Calgary, Division of Palliative Medicine
  - Medical Director, Health System Ethics and Policy, Health Quality Council of Alberta
  - Ethics Advisor or Committee member with a number of provincial and national government and health agencies

My objective today

- Stimulate thinking from a somewhat different direction, about a conflicting public health imperative.
- My prod regards both the problem and potential solutions



Who I am thinking about today

Scope

- I'll be addressing my comments to the part of the system involved with caring for people where they live congregately.
- They are uniquely vulnerable, necessitating living in and being cared for in care facilities that are their homes, with similar others.
- We'll use the term congregate living care settings.
- Including care homes providing varying levels of care intensity and complexity as well as residential hospices for end-of-life care.
- Mostly elderly people, but certainly not always.
- Will not be directly addressing acute care facilities.

Let’s first acknowledge people’s dedication and efforts

- Our health system leaders and facility operators have done quite a remarkable job in meeting the challenges of a novel, dangerous pathogen. They have adapted intelligently and with strong commitment to principles they are operating under.
- Staff and leaders in our facilities work with exemplary dedication in uncertain and difficult conditions. They are also vulnerable, together with their families.
- Families, advocates, researchers, policy-makers, businesses are all working really hard, and creatively, in tough circumstances.

Solidarity

Corollary are some procedural values

- **Transparency** – regarding actions; what we know; what we don't know; how, when and through whom we will communicate with you.
- **Inclusivity** – how we go about collecting the views of people and including them in decision-making; assure that those most affected are not just informed, but are at decisional tables in some manner.
- **Subsidiarity** – support that decision-making levels, where appropriate, are closest to the interface of impact; here, where care and accommodation are provided.
- **Appeals mechanisms and revisability**

Where are Canadians dying from CoVID-19?

- According to CIHI, as of May 25, 2020:
  - 81.1% of all deaths from CoVID-19 in Canada were in long-term care (total CoVID-19 deaths per million population = 175.5).
  - This is almost double the average for 16 OECD countries.
  - Next highest was Spain at 66.1% (total CoVID-19 deaths per million population = 574.1).
  - Australia was 27.5% (3.4 CoVID-19 deaths/million pop.), some countries less than 20%
  - Also have the third highest percentage of LTC Residents age 80+

- Canadian Institute for Health Information. *Pandemic Experience in the Long-Term Care Sector: How Does Canada Compare With Other Countries — Data Tables*. Ottawa, ON: CIHI; 2020. accessed November 15, 2020.

What is the conundrum?

- We feel compelled to keep vulnerable people safe from contracting this illness and very possibly dying;
- And also wish to keep our health care workers and their families safe;
- While we avoid the unintended major consequences of what we have viewed as a required isolation strategy.

In other words

- We have a duty to protect – to minimize death and infection spread to others
  - And remember this is a killing illness in the population we are speaking about
- While we also have a duty to not cause other, and perhaps worse harm, while we are protecting people from death
- Have we done one at the expense of the other and can that be justified?

Public Health imperatives for addressing a contagious illness

- Steps taken by the Chief Medical Officer of Health, under the legislation are meant to:
  - Suppress the illness in those who may be infected
  - Protect those not already exposed
  - Break the transmission chain; prevent spread
  - Remove the source of infection

- Adapted from *Record of Decision – CMOH Order 29-2020, July 16, 2020, Alberta Health*

But it doesn’t end there

- Our leaders are cognizant of
  - the consequences of social and economic disruption
  - and meant to protect from unintended negative consequences to health and overall wellness

Substantive values

- These motivations are informed by, and animate societal values:
  - Use communal resources to protect all from harm, to the degree possible
  - Maximally protect people who are particularly vulnerable

Public Health Agency of Canada characterizes it this way

- Foundationally, promote trust and a fair distribution of burdens and benefits
- Do this by
  - respecting persons, communities and human rights
  - Promoting well-being
  - Minimizing harm
  - Working together

PHAC

- Balancing well-being and minimization of harm requires attention to:
  - Effectiveness – can implement a policy and thereby achieve goals
  - Proportionality – balance benefits and risk of harms; measures proportionate to the threat and risks; use least restrictive measures
  - Reciprocity – support those facing risks while they protect others, and minimize burdens by those facing risks
  - Precaution – take action when necessary even in the face of scientific uncertainty, while always seeking further scientific evidence

PHAC – Procedural considerations

- Accountability
- Openness and transparency
- Inclusiveness
- Responsiveness
- Intersectionality
- Adapted from *Public Health Ethics Framework: A guide for use in response to the COVID-19 pandemic in Canada*, 2020.

What might be the problem? (1)

- In a practical and entirely plausible view….
  - Inadequate funding, preparation in this sector
  - A disadvantaged focus

  - Recommended reading:
    - Estabrooks CA, Straus S, Flood, CM, Keefe J, Armstrong P, Donner G, Boscart V, Ducharme F, Silvius J, Wolfson M. Restoring trust: COVID-19 and the future of long-term care. Royal Society of Canada. 2020

Federal funding to individuals

- *Canada's 'generous' COVID-19 income supports vastly outpaced other developed nations: OECD* – Jesse Snyder, National Post, Nov 14, 2020.

- Reported that household incomes increased by 11% (2nd quarter, 2020);
- Economy contracted by 10% in the same time period

- Household savings also increased.

- Meanwhile, Rome is burning….

Media headlines

- *Nursing homes under siege again* – Sharon Kirkey, Calgary Herald, 13 Oct 2020.
- *Strict COVID-19 protocols are leaving seniors lonely, depressed and wondering: Is it worth it?* – Maclean's, November 2020
- *Should more be done to protect seniors facilities as COVID-19 cases rise in Alberta?* – Vinesh Pratap, Global News, November 13, 2020.

Policy interventions by 1000th case nationally (CIHI May 25, 2020)

- LTC infection control and audit
- LTC rapid response prevention and control
- Isolation wards for infected LTC Residents
- CoVID-19 testing of all LTC Residents and staff
- Hazard pay
- Recruitment and surge staffing
- 1:1 staffing for LTC Residents with dementia
- Funding for PPE
- Enforced restriction of visitors to LTC

- In Canada – only the last item was a policy intervention by the date of the 1000th case (Mar 20)

What might be the problem? (2)

- Through the lens of a deeper view…..a flawed mental model of elderly and vulnerable persons and of family and community responsibilities towards them
- This flawed model includes certain notions about the ‘health care system’ and its’ authority, accountabilities and duties that absolves ‘community’ of authority and responsibility, and perhaps promotes distance, or denial of “place” – ie. to be present in people’s living.

Some of the language we have incorporated into our thinking

- Demand quality and safety
- Trained professionals and managers know best
- Need for efficiency
- The ‘system’ will manage things for us
- “we own / we run”
- Visiting hours are logical and necessary
- It’s about care and protection for all in the congregate setting

The other sides of the three-sided coin

- An interesting model to contemplate:
- Move from: there is a place set up to care for X;
- To: Can we, as family be invited in to assist in X's care;
- To, eventually: I appreciate you caring for X while we cannot be there.
- (…at least for Residents who have family or community to support them)

And a second underlying assumption problem (3)

- Our attention is focused on death
  - preventing it at almost all cost; and
  - measuring performance via death statistics; and
  - asserting it is the pinnacle risk.

And a second underlying assumption problem (3)

- When our attention should also be focused on
  - addressing the living and accompanying experience for those still vulnerable citizens who will not die; and
  - addressing the living and accompanying experience for those who contract the illness and will die; and
  - those preparing for death from other causes.
  - measuring performance via measures of suffering and its' attenuation, and positive measures of healthy experiences.

Daily CoVID-19 data

Claim

- Cannot eliminate the risk of contracting CoVID-19 – can only mitigate it and reduce the risk acceptably
- Cannot eliminate all other harms or the risks of magnifying those harms – but can definitely reduce and minimize the other harms by a concerted push to think differently along with high expectations/demand for success.

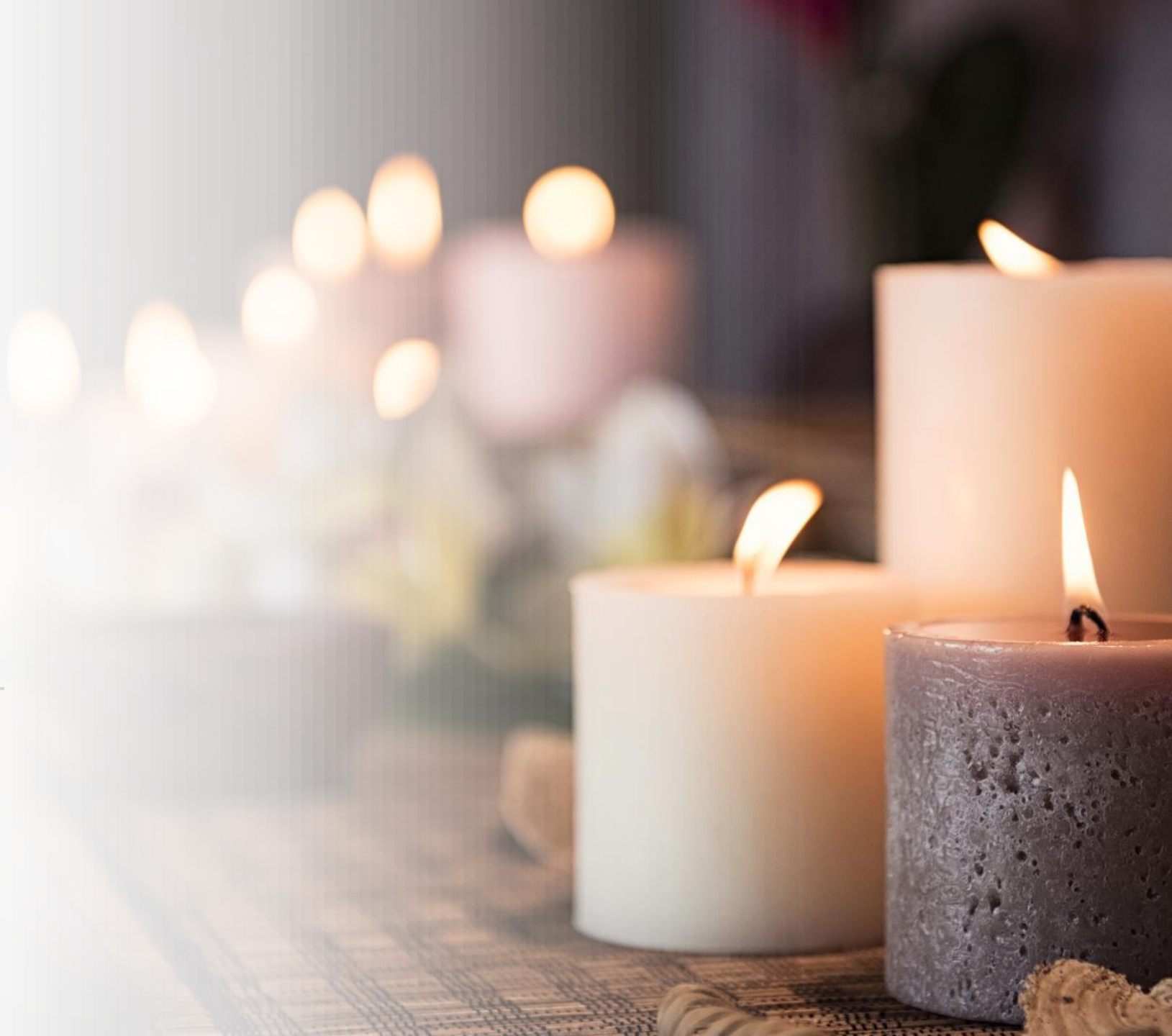
Risk matrix

- likelihood of event X occurring;
- nature and degree of the harm if event X occurs

Claim

- Accept that some death will occur
- Attend carefully to optimizing the dying experience

The special problem of COVID visitation during care at the end of life



Challenging these societal premises

- Death is to be avoided at all costs as the primary measure
- Death is much worse than suffering and poor living

Challenging these societal premises

- The health system owns the problem and solutions
- Long term care is primarily a care facility

Challenging these societal premises

- Families and visitors are a vector of infection – keep them out if you can
- They are a “nice to have” part of the care team… maybe

Challenging these societal premises

- All families, residents and staff feel the same way

Health Quality Council of Alberta surveys

- For the time period from late March until late July, 2020.
- Survey responses from 9625 family members and 387 Residents in Continuing Care sites in Alberta.
- In-depth interviews with 43 Residents, including both outbreak and non-outbreak sites.
- https://hqca.ca

Challenging these societal premises

- Any strategy needs to be “fair” ie universally applied,
- Consider, instead, targeted facility or regional pilots to learn if innovations can assist as we prepare for the next wave or crisis (think of AB traveler trial)

Challenging these societal premises

- Cannot afford better staffing ratios, training.
- AB $/capita for health care vs LTC care staff ratios and care aide training hours

Challenging these societal premises

- Family members cannot become fully integrated members of the circle of care in these care/living facilities – there are too many legal, operational, risk, training barriers

What ought we do?

- Immediately
  - Practical ideas, such as rapid testing capacity (mobilize resources differently)
  - Put money and prep time into bringing the designated support person within the formal care circle (faster and cheaper than hiring others)
  - Processes such as pilots in selected areas
  - Hire expert folks to be educators, greeters, guides to relieve these burdens from care staff. Train volunteers for similar roles.
  - Mobilize the community differently – support the designated support person maximally, via community action – compassionate communities approach. Designated support person can be semi-isolated in their homes if necessary, while being supported in other ways to be able to do so.
  - Philanthropy
  - E-sim

But that all costs money, you say!

- Agreed.

What ought we do in the long term?

- There are many calls to action that experts have made, including national standards, enshrining accountabilities and expectations and rights into something akin to the Canada Health Act for LTC
- New building designs (safe access, single rooms, space for family care, air flow, infection control spaces)
- New staffing models
- Better training for staff and families
- Better funding, support more research
- Develop “compassionate communities of care” models

- Read about them

End claims

- Over the very long term, we have all – **as a society** - failed these most vulnerable people, and their families, and our staff.
- That is despite great efforts by many care staff, managers, operators, volunteers, family members.
- We need to be thinking about this all from a different set of assumptions and biases.

End Claims

- There are important things that can be done by:
  - Governments and funders
  - Philanthropists, researchers
  - Facility operators and health system operators
  - Families
  - Staff
  - The community

But first….

- We will have to alter our mental model about the place of family members and communities within care models for people who live, while being dependent, in care homes;
- As well as for the expected place of family members in the circle of living and care for people preparing for death.

Thankyou

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