LIFE, DEATH, & DIGNITY

A THREE-PART COMMUNITY DISCUSSION SERIES

A FINAL REPORT

APRIL, MAY, & JUNE 2020

VICTORIA HOSPICE

VIRCS

THE TABLE
CONVERSATIONS + COMMUNITY

VICTORIA SOCIAL INNOVATION CENTRE

Canadian Heritage   Patrimoine canadien

The Life, Death, and Dignity community discussion series was a collaborative project involving Victoria Hospice, This is Table Talk and the Victoria Immigrant and Refugee Society and Centre, and took place on April 16th, May 12th, and June 18th of 2020. Due to COVID-19 related restrictions, the series was hosted virtually through Zoom and was attended by a total of 45 community members, and 10 Victoria Hospice staff members. General feedback from the audience was positive.

BACKGROUND

Discussions around death and dying are often taboo, considered morbid, and generally avoided. However, to achieve a "good death," where an individual dies feeling dignified and respected, requires these conversations to be had. A "good death" is often defined as a death where the person is free from distress and suffering, and care is accord with the person's physical, emotional, spiritual, and cultural wishes. Palliative end-of-life care aims to relieve suffering for patients and families, improving quality of life and supporting a "good death".

Many factors play a role in determining access to palliative end-of-life care including race, socioeconomic status, financial status, education etc. This has led to debates on whether achieving a "good death" is a privilege not everyone has, bringing forward the question of equity in end-of-life care. With the growing diversity in our broader communities,

the question of interest was whether care providers are meeting the diverse needs of community members during their provision of care, especially the needs of voices seldom heard such as the BIPOC community (Black, Indigenous, and People of Colour).

Victoria Hospice's (VH) mission is to enhance the quality of life for those facing life-limiting illness, death and bereavement through patient and families centred care, education, research and advocacy. As such, VH wanted to find out what a good and dignified death meant for our communities, and what challenges and opportunities to improve care the broader community identifies. imultaneously, VH wanted to create a space where community voices are not only heard, but also lead the discussion itself, providing the opportunity for "experts" to be active listeners.

EVENT DETAILS

In **February 2020,** the research team at Victoria Hospice approached This is Table Talk, a local organization focused on increasing dialogue and community for self-identifying people of colour, and the Victoria Immigrant and Refugee Centre Society. The idea was to create a community dialogue event where seldom heard voices could come together to share their perspective on death and dying, followed by a presentation of life and death celebrations cross-culturally. Some initial questions framing the conception of this event were: what defines a good death, is this being achieved, and do people feel safe and respected in medical care settings (clinic, hospital, etc.).

COVID-related public health regulations in mid March prevented an in-person event to be run but light public outreach revealed that there was still an appetite in the community for the topic. The initial idea was then adapted into a three part online community discussion series titled Life, Death, and Dignity, with each session on each of the topic respectively. The events took place on April 16th, May 14th, and June 18th of 2020, and a total of 45 community members, and 10 Victoria Hospice staff members participated in these sessions.

Advertising was marketed through the Victoria Hospice internal newsletter, website, and social media. Collaborators also promoted the sessions through their social media, email, and word of mouth. Registration was managed through Eventbrite and was free.

The mechanism of how This is Table Talk holds space for community voices is indigenous in nature, and is as follows. In the centre of the room is a table where speakers are invited to sit and share their perspectives on the topic, surrounding the table is a listening circle where all other participants (and hospice staff members) listen to and validate the conversations which unfold. At any moment, a speaker can leave the table and join the listening circle, while simultaneously a listener may join the speaker table if there is space. This creates a fluid transfer between listeners and speakers without interrupting the conversation. This mechanism was adapted to fit into the online Zoom format.

TARGET AUDIENCE

Greater Victoria community members who are interested in or have been affected by death. This particular series prioritized seldom heard voices such as members from BIPOC, and LTBQ+ communities. Victoria Hospice and end-of-life care educators and providers were invited to participate as listeners and a resource for questions on end of life care.

ORGANIZERS & FACILITATORS

Annie Do & Eshu Martin (VH), Parker Johnson (This is Table Talk), Ariel Reyes Antuan (VIRCS) with input from Helena Daudt (VH) and additional support from Anke Krey (VH), Brittany Clarke (VH) and Theresa Brown (VH).

EVENT STATISTICS

Date	Venue	# of Registrations	# of Participants (excluding staff)	# of event facilitators	Partners
16-Apr-20	Zoom	15 / 15	10	4	VIRCS & Table Victoria
12-May-20	Zoom	30 / 30	20	4	VIRCS & Table Victoria
18-Jun-20	Zoom	40 / 40	25	4	VIRCS & Table Victoria
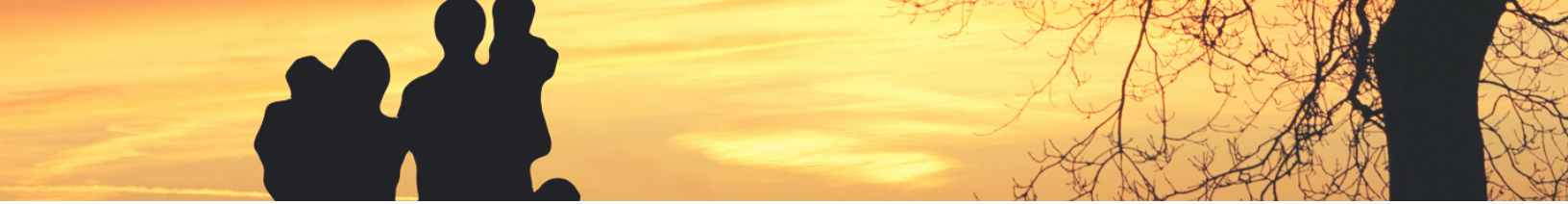
The first session focused on understanding what a good quality of life meant to community members outside of a medical context. The event took place on National Advance Care Planning day, which provided opportunity for community members to reflect on important values, and spiritual, physical, emotional and cultural needs which give them life. A life well lived meant many different things to different people, but the community dialogue unveiled some shared perspectives. Community members identified that a difference existed between the terms living and surviving, highlighting that living only starts when basic needs are met. A life well lived encompassed more than completing every day tasks, as emphasis was placed on elements of creating and maintaining human relationships such as quality of friendships and deep social connections; and the ability to pursue and focus on activities that brought meaning. Feelings of unbalance, distress, and anxiety and can hinder a sense of living, and the ability to cope and overcome these challenges comes from knowing where to turn to for trusted supports and resources.

Spiritual health also played an important role in maintaining a good life, which is often overlooked. Maintaining spiritual health doesn't require being connected to a particular religion, but can come from anything that provides meaning and provides connection beyond just the physical self.

Covid-19 and the repercussions of the pandemic have shifted how people view living and life in general. Though the same measures impact everyone, these impacts are not evenly distributed.

For ex. one community member mentioned how the isolation has impacted their friend, who is deaf, in much different ways than others. Another community member spoke of disenfranchised death and grief, and how some deaths are more openly acknowledged than others. In addition, it was thought that conversations on what constitutes a good life, and subsequently a good death, are stigmatized because of the lack of understanding and acceptance of different backgrounds or beliefs. Creating spaces which encourage safe and open dialogue for people of all backgrounds is needed for fostering both a deeper reconnection with ourselves, and others.

KEY THEMES

- **Basic needs such as food, shelter, water, and education need to be met before opportunities can arise for meaningful activities**

- **To live out a good life, one must pursue what is physically, mentally, spiritually, and emotionally important to them**

- **The ability to connect with others is one of the most important elements for maintaining a good quality of life and at the end of life**

- **The seemingly smaller things in life can play an important role in defining values**

- **Stigmas around conversations on life and death can be addressed by providing safe and open discussion spaces**

- **Conversations on life and death should be acknowledged and appreciated regardless of culture, belief, or values**

The second session focused on exploring and understanding what a good death meant to community members, and what mechanisms are needed to achieve. Discussion questions for this session involved COVID-19, barriers, communication, end of life care, and relationships. Community members identified that the current culture does not allow conversations about death and dying to occur with ease – partly because of the tendencies to shy away from tough situations while embracing "showing off our best selves". It was also mentioned that a good death is subjective, and a lot to do with how each person defines themselves and what is important to them.

Having a sense of fulfillment or completion in relation to the individual's purpose was an iterative theme. Deaths are contextual, and it was agreed that it was impossible to determine what makes specifically a good death for someone else. Families and caregivers also handle death in diverse ways, including both individually and culturally. Sometimes issues can arise when what the person wants for a good death may not align with their loved ones idea of a good death. Cultural practices hold great significance for people, and providers must strive to understand, respect, and uphold a person's culture and views - one cannot define a good death for someone else based on their own values.

KEY THEMES

- **There is no universal "good death", but to achieve one requires the individuals cultural, spiritual, physical, and emotional needs to be met**

- **the person must be fully seen, heard and acknowledged, before their wishes and values can be acurrately executed.**

- **There are many potential barriers to a good death, including access, education, race, income, loved ones, and clashing values.**

- **COVID-19 has increased discussions about death, and subsequently how some deaths are valued higher than others**

- **Spirituality and religion does seem to have a place in the health care system, particularly in conversations with providers, but spirituality is not something that can be "left at home", it is part of the person**

- **How death is portrayed and perpetuated in media influences our reluctance to discuss it**

The pandemic has spotlight the topic of death and dying due to the daily reports on the number of cases and deaths, Community members acknowledged this may be because Covid-19 is impacting more people in privileged positions, while other deaths (such as by drugs or mental health) have persisted for a long time but are rarely spoken about.

Finally, spiritual health was touched on heavily with conversations around how religion and spirituality is often a shunned topic in institutional environments such as the workplace, or school. There is an expectation that religion be separate from the person in these environments, but disconnecting spirituality can make the topic of death harder to approach, especially when it is avoided in a provider-patient setting. There should be more movement with providers creating safer spaces to talk about spirituality, and religion in relation to death. The power dynamic within the medical systems already place patients in uncomfortable positions, and conversations on culture and spirituality, while important to the community members, seem to have no place in patient-provider exchanges.

The third session focused on what was needed to achieve or maintain dignity at end of life. Overall, there was a consensus that the mere act of maintaining dignity was still a constant struggle in everyday life for community members who have been historically and/or are still facing systems of oppression. This reality is exacerbated for community members who have intersecting identities, for example a person who is queer and black, or a person who has a disability and is also Trans.

It was not enough to be acknowledged by providers, but to be seen, heard and known. Community members felt empowered and dignified when their providers and caregivers genuinely took the time to understand their story, experiences, and humanity beyond just being the patient, or "another body in a bed". Labels, such as being a "difficult patient" were dangerous and stripped away dignity by dehumanizing the person. Even though classification is meant for organizing and faster processing, it can slow down delivery of care because of the way it boxes people and strips away their humanity.

Not having the capacity to voice a need is a behaviour learned by living and growing in unsafe environments. Someone who is different from societal norms will naturally feel uncomfortable to speak about their needs around death and dying. There is still fear of engaging in these types conversations because of the fear of isolation.. This fear drives people to censor themselves before they even ask if a spiritual or cultural practice is okay, they fear that the practice is not socially sanctioned like how some religions are e.g., (Christianity, or Islam). We need to build the capacity for everyone to feel safe voicing what they need, and to create spaces where these complicated and uncomfortable conversations can live.

The professionalizing of end of life care, and how capitalism has seeped into the medical system was talked about. There is an imbalance of power, and information asymmetry that exists between professionals and the patient, and without the ability for both parties to be relational with each other this imbalance can disempower and sometimes censor the family and patient from communicating what they need. How can we create a reciprocal relationship between the patient and provider?

Several community members mentioned the importance of learning techniques and strategies for resilience, so that they can not only support themselves and each other, but restore the loss of autonomy often felt at end of life. One community member explained how she wish she was provided the information to know what to expect during the dying phase, so that she could have better supported her loved one.

Systems change is complex, and messy. When we approach building new policies, especially around culture and diversity, the intention is that the policy will create an environment where people can be curious and relational with one another. The reality is that policy creates a pressure to practice, and that practice is coded a certain way which materializes as just another box to check off. Even though new tools and policies are created to help increase access to cultural and spiritual practices, how it's carried out can introduce unintended barriers. Educational modules and cultural safety or competency need to include skills that encourage lifelong learning and adaptability.
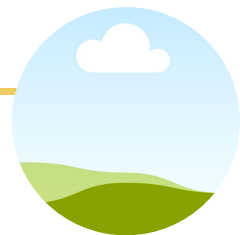
GRAPHIC RECORDING

For part 3, a graphic recorder was hired to capture the key themes arising from the conversation in a visual display. This allowed for real-time translation of conversations into text and pictures. It also gave participants to absorb content on a visual level. The graphic recorder did three things simultaneously: she listened for key ideas, synthesized them, and documented them in visual form. Some elements of the graphic below were used for emphasis in the part 3 summary.

KEY THEMES
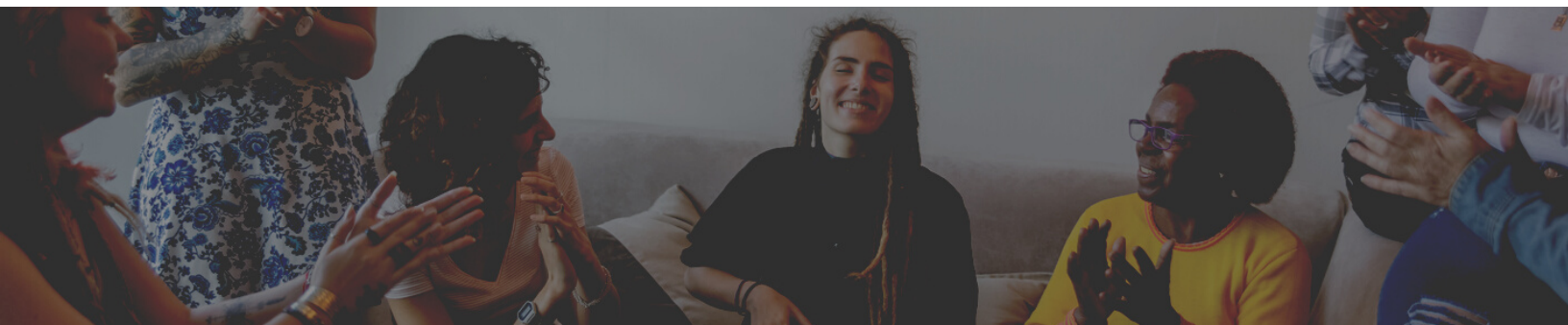
EVENT FEEDBACK

Victoria Hospice created an online feedback survey on Survey Monkey, which was sent out to attendees at the end of each session. Feedback was also collected live during the sessions by way of participant engagement using reaction buttons; on average around 1/3rd of participants actively used a "thumbs up" or "clapping" reaction during the course of the community discussion to indicate whether the conversation was resonating with them. The survey response rate was low with only 6 responses in total (13%). Most of the comments were positive about the event, format, and the topic and discussion opportunity.

FEEDBACK SNAPSHOT

"Important topic, well rounded discussion"

"Listening to each speaker's experiences and perspectives. The speakers were respectful and knowledgeable"

"I have a lot more appreciation for how systems fail people and perhaps more likely to explore more about others' experiences and share what it's like for others like me. Systems aren't perfect for us either. Maybe we need to look for our commonalities as humans around the dying experience. I think the session really focused on barriers. Black, white, brown, we all are going to die and we all have thoughts about that particular event as humans."

"To have the opportunity to be involved in a cross cultural discussion. Opportunity for other community members to ask questions/share stories. The eclectic experience of the panel members."

CONCLUSION

Overall, this three-part series was successful in creating a space where community members felt safe to talk about death and dying, their experiences, and their needs and barriers regarding end-of-life care. The participant feedback was largely positive but it is important to note that a couple comments in session three revealed that some participants felt uncomfortable with the focus on barriers and intercultural concerns, and felt like not enough was said on the topic of death and dying. One comment mentioned that the community's emphasis on the impacts of colonialism made them feel unsafe..Response rate of the feedback was also low, therefore an alternative method to elicit feedback will be sought for future events. While this event was successful, Many community members mentioned how positive having these spaces created was for them, This is only the beginning of our learning journey, but we recognize that eliciting conversations with the public is important for a co-learning experience, We hope to continue more community engagement events such as these, and more effort will be placed on ensuring that all participants feel respected and safe for future events.