



Covenant Health
Palliative Institute

A Safe Space to Talk About Death

A Report on
Death Cafes in Alberta

March 2022

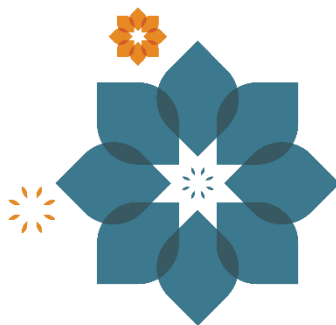


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Introduction

Death Cafe is a grassroots “social franchise” founded by Jon Underwood and Sue Barsky Reid in 2011 in London, UK, inspired by Swiss sociologist Bernard Crettaz’s Cafe Mortel model. The official purpose of Death Cafe is to “to increase awareness of death to help people make the most of their (finite) lives.” Between 2011 and 2021, over 13,000 Death Cafes took place in 81 countries around the world.

A Death Cafe features unstructured, group-directed conversation over refreshments. A facilitator invites conversation and upholds Death Cafe guidelines that:

- the event is free of an agenda, objective or themes
- it operates on a not-for-profit basis
- conversation is respectful and confidential, and
- it is not a grief support or counselling session.

Anyone who follows the guidelines may advertise their event as a Death Cafe. Those who do not comply have been asked to do so or to refrain from using the Death Cafe name.

Death Cafes are popular with hospice and palliative care organizations. There are strong parallels between palliative care’s focus on enhancing quality of life and the Death Cafe objective to help people “make the most of their (finite) lives.” At the same time, the impact of Death Cafes and their relationship to palliative care are not well understood.

As part of a project to raise public awareness of palliative care in Alberta, the Covenant Health Palliative Institute undertook an investigation of Death Cafe. The purpose was:

- to evaluate the state of the research on Death Cafes
- to assess the uptake of Death Cafes in Alberta
- to better understand the strengths and limitations of the Death Cafe format, and
- to determine whether Death Cafes may play a role in raising public awareness of palliative care in Alberta.

The report that follows outlines the key findings of a literature review and environmental scan as well as a survey and focus groups conducted with Alberta Death Cafe facilitators in the spring of 2021.





Literature Review

A review of the academic literature was conducted using the search term “death cafe.” The search was not limited by date, population or setting, but it was limited to English-language sources. Included were: research articles, conference abstracts, and opinion pieces by authors who attended or facilitated a Death Cafe. Excluded were: opinion pieces not based on first-hand experience with Death Cafe. Twenty-three sources met the inclusion criteria.

Findings

Demographics

Death Cafe participation in the United Kingdom and the United States appears highest among those who are white, female, baby-boomers, work in health or death-related fields and have experienced the loss of someone close to them (Baldwin 2017; Green 2016). But the broad global appeal of Death Cafe suggests the possibility of more diverse participation by addressing barriers: “If they are to become more open and accessible it is necessary that consideration be given to aspects such as location, timing, publicity, style, facilitation and ‘ownership’” (Green 2016).

Applications in Health Care

Death Cafes have been used to increase health care providers' comfort talking about death with patients (Howarth 2018; Nelson 2018) and to help health care providers process their own experiences with death (Hammer 2019; Moynihan 2015).

Impact

The global response to Death Cafe suggests that it is meeting a social need for safe spaces to talk about death, but there is no clear evidence that participation in a Death Cafe leads to behavioural change (Miles 2017; Richards 2020). Some participants have reported increased comfort talking about death and dying (Howarth 2018; Nelson 2018; Pruett 2014).

State of the Research

Despite significant interest there is “a dearth of literature that explores the phenomenon in any substantive way” (Richards 2020). Research has also not addressed the extent to which palliative care emerges as a subject of conversation at Death Cafes nor the nature of discussion on this topic.



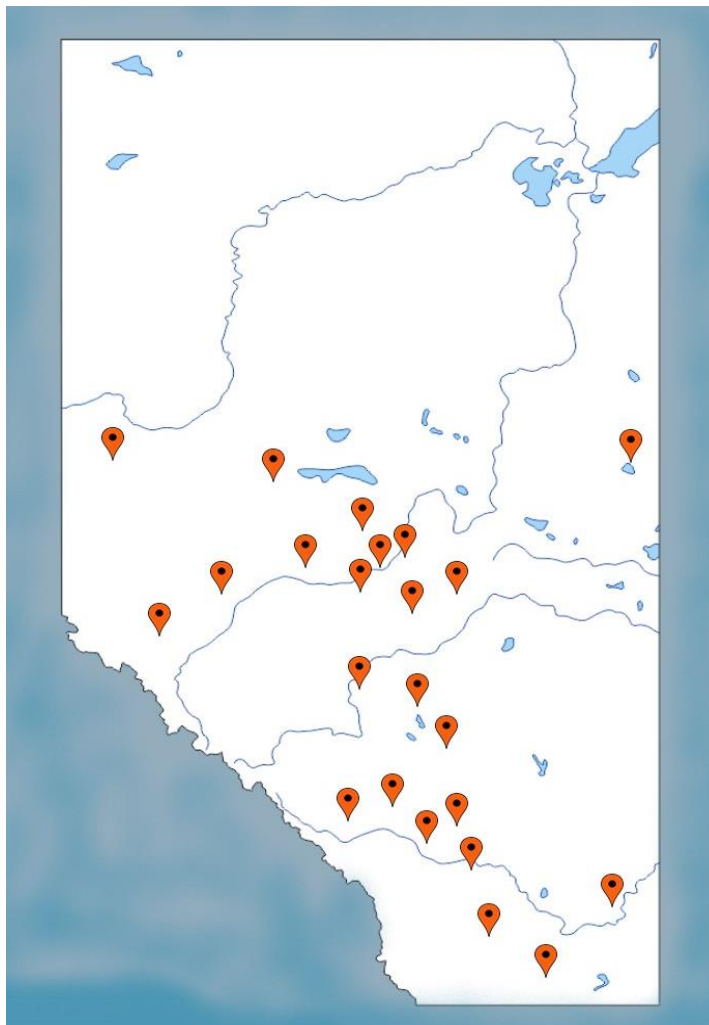


Death Cafes in Alberta

The Death Cafe organization tracks the number of Death Cafes held around the world by encouraging facilitators to list their events on the [Death Cafe](#) website. This also serves as a means of advertising.

Past Death Cafes are searchable by location on the website. A systematic search of these listings showed that:

- Forty individuals in 23 locations across Alberta facilitated Death Cafes between 2013 and 2021.
- The Alberta Hospice Palliative Care Association and eight local hospice or palliative care societies have hosted or sponsored Death Cafes in Alberta.



Map

Locations of Death Cafes held in Alberta between 2013 and 2021



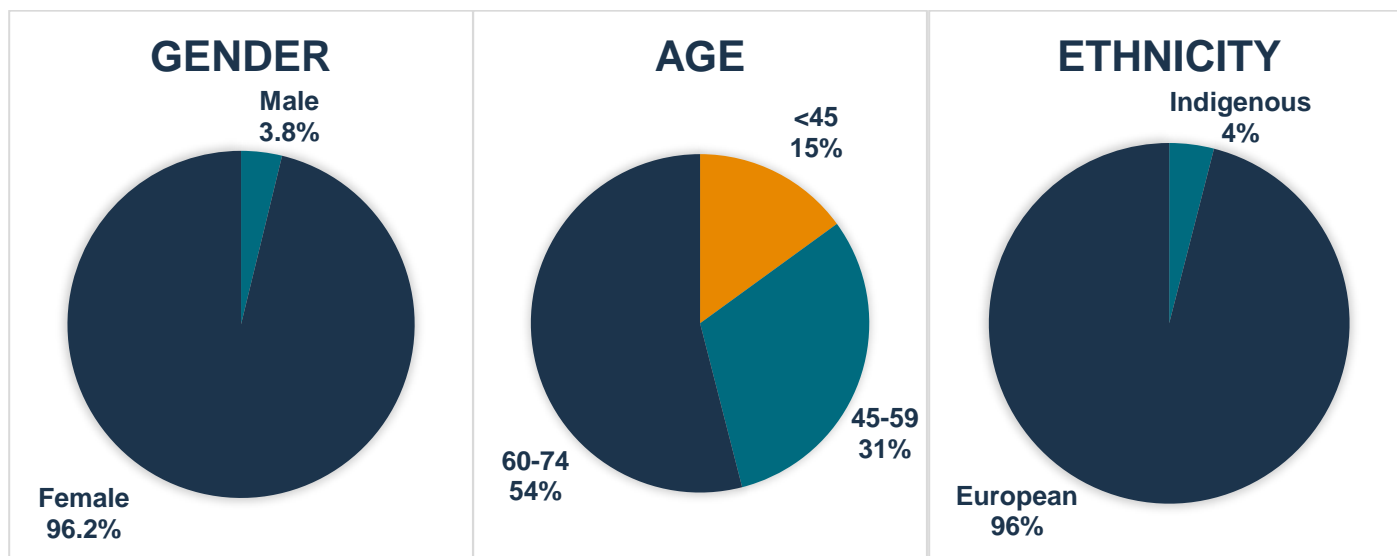


Facilitator Survey

A Google search for the 40 facilitators identified through the Death Cafe website yielded contact information for 34 of the facilitators, who were contacted and invited to participate in an online survey (see [Appendix 2](#)). Twenty-six surveys were completed (76% response rate).

Demographics

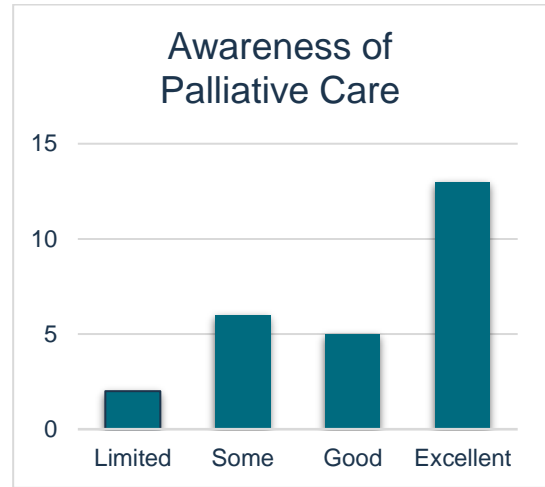
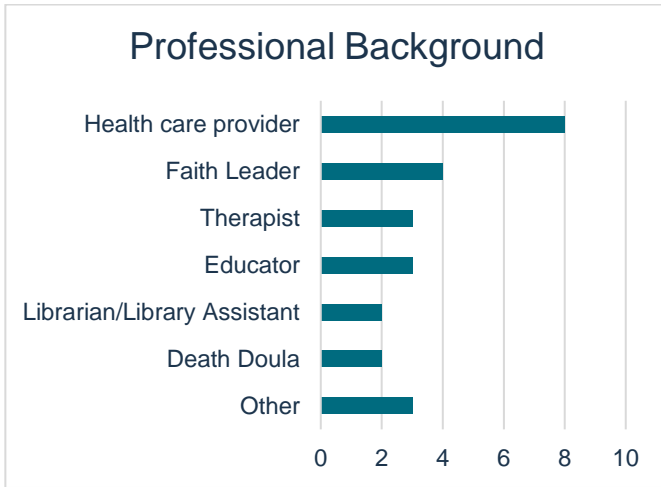
Survey respondents self-identified as follows:



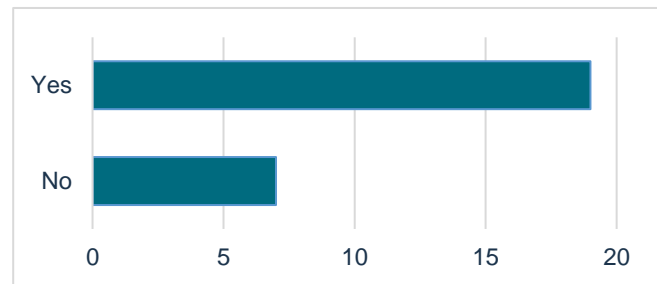


Facilitators' Backgrounds

Number of Respondents = 26

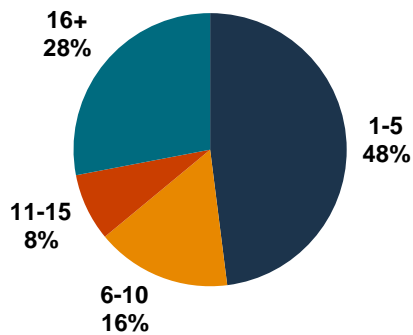


Has someone important to you received palliative care within the last ten years?

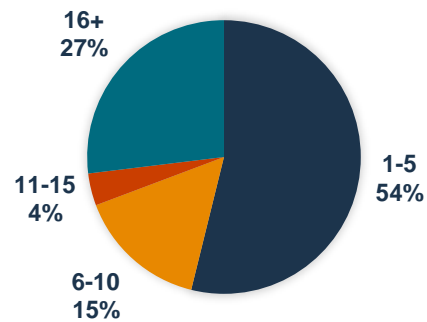


Experience with Death Cafe

Number of Death Cafes Attended



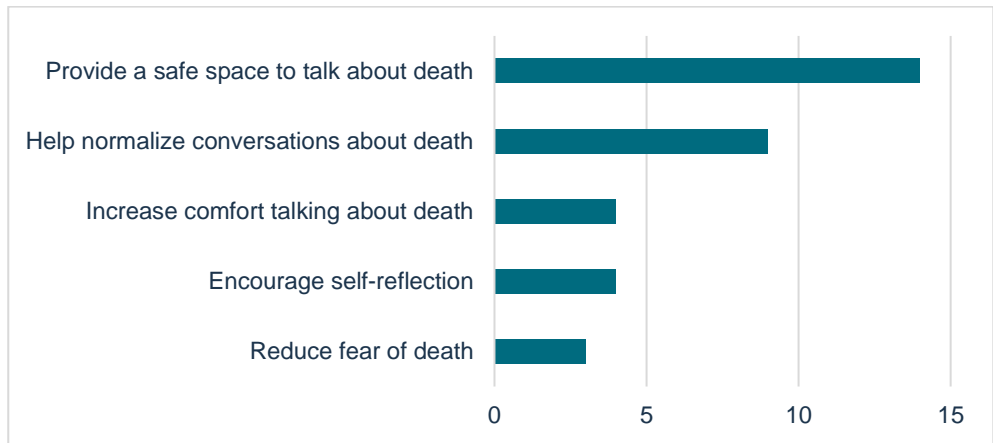
Number of Death Cafes Facilitated





What is Your Goal in Facilitating a Death Cafe?

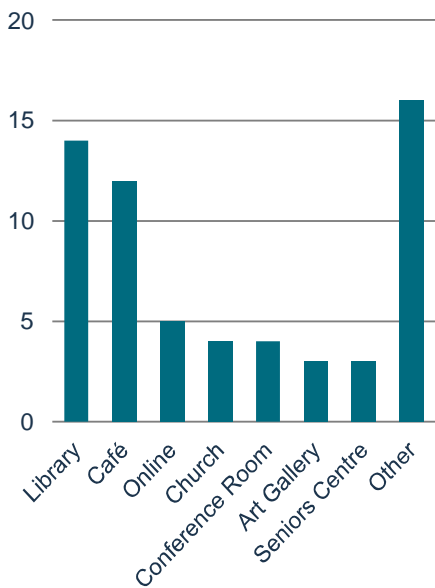
Open-Ended Question



Death Cafe Logistics

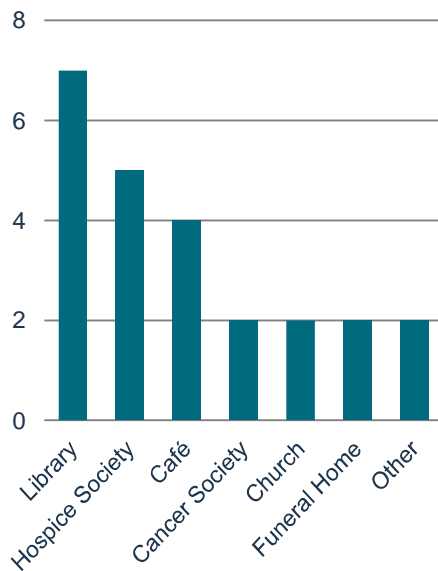
Facilitators were asked what venues they used, what organizations they partnered with and how they advertised.

Venues

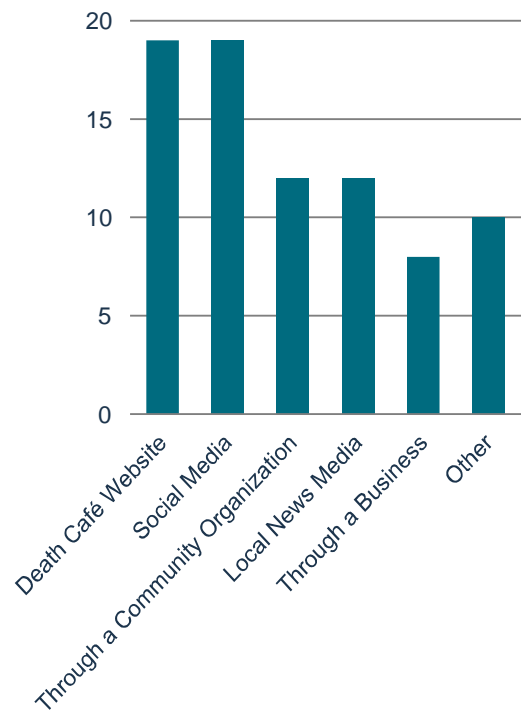


Sponsors*

*Donated Space or Refreshments or Co-Organized the event



Advertising Platforms

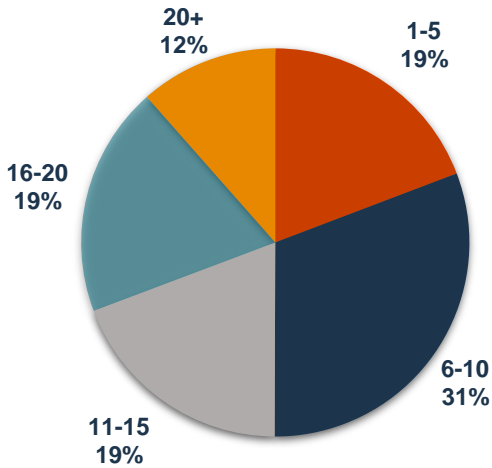




At Death Cafes in Alberta

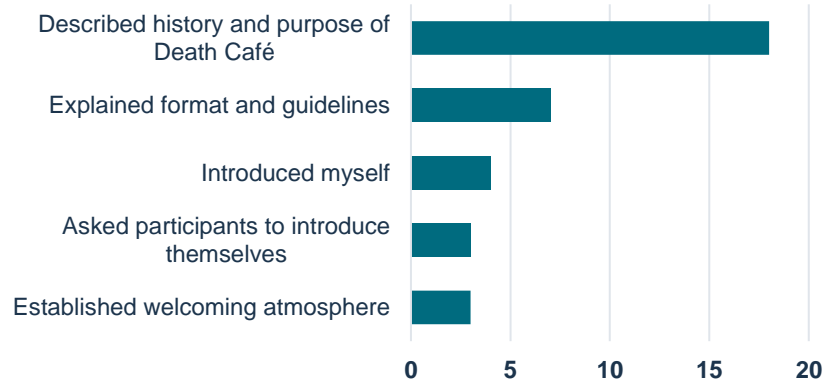
Average Attendance

Number of People

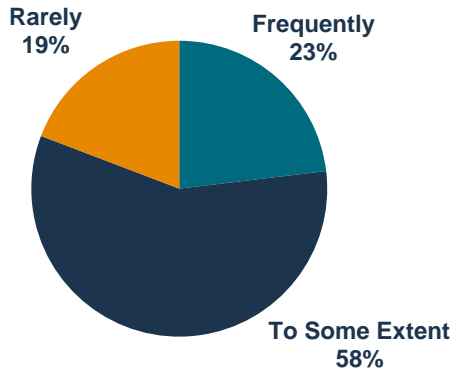


How Did You Introduce the Death Cafe(s) You Facilitated?

Open-Ended Question



Frequency of Conversation About Palliative/End-of-Life Care



Frequency of Conversation About Advance Care Planning

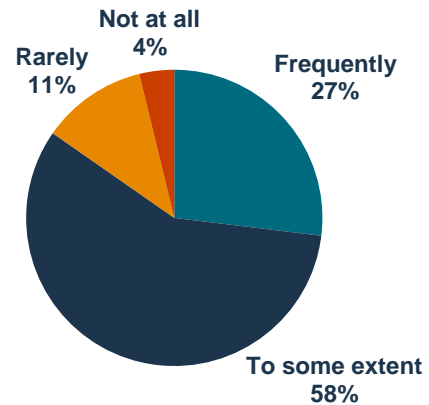




Image: Word cloud of frequently used words from open-ended survey responses

Key Survey Findings

Demographics

The demographic profile of Alberta Death Cafe facilitators is consistent with British and American studies that indicate Death Cafe facilitators and participants in those countries are most likely to be female baby-boomers of European ethnic origin who have personally experienced the death of someone close to them.

Venues, Sponsors and Advertising

Public libraries were the most frequently identified venue and sponsor of Alberta Death Cafes, while hospice societies were the second most frequent sponsor and cafés the second most frequent venue. The Death Cafe website and social media (particularly Facebook) were the most popular platforms for advertising Death Cafes in Alberta.

Discussion of Palliative Care and Advance Care Planning

Self-reported awareness of palliative care and advance care planning on the part of Alberta Death Cafe facilitators is above average when measured against public polling, and the extent to which these topics are subjects of conversation at Death Cafes in Alberta is also higher than expected from the research literature. This may be an indication that people attending Death Cafes are, like Death Cafe facilitators themselves, likely to have experienced the loss of someone close to them. We are unable to assess the content or accuracy of Death Cafe conversations about palliative care.



Facilitator Focus Groups

Eighteen of the 26 individuals who completed the Death Cafe facilitator survey indicated a willingness to be contacted for further information. These facilitators were invited to attend one of two 60-minute focus group sessions. A total of 15 facilitators participated in a focus group.

Focus group discussion centered on:

- the strengths and limitations of the Death Cafe format
- death-related needs in Alberta, and
- the potential for Death Cafes to contribute to greater public awareness of palliative care.

Many of the facilitators that participated in the focus groups introduced Death Cafe to their communities, and some have many years of experience facilitating these events. Over the course of the discussion they expanded on information provided in the survey and offered their insights on the role of Death Cafe in Alberta.

Practical Advice from Facilitators

Set the stage with good food and drink

“We always have great tea, because Jon [Underwood] said you have to have great tea...And we always have great cakes.”

“Part of the fun was coming up with the death menu. You know, we’d have devil’s cake and angel food cake and death by chocolate. And so that created a bit of ease into it for some people too.”

Be an active facilitator

“I did have a couple of times with some people that I needed to ask them not to monopolize the table and talk about their beliefs...Sometimes there were people who were getting very angry with somebody else, or a table that was off topic. That’s one of the things about the format that I don’t think it can just be loosey goosey...that the facilitator actually is facilitating.”





What are the Strengths of the Death Cafe Format?

It provides a safe space to talk about death

“It was just such a good structure because it just kept it so safe for people and there wasn’t an agenda.”

“There’s no one who hasn’t been impacted by death but there’s not really that many places they are able to talk about it.”

“And people have said to me – that is such a great process, the little tables, the tea, the openness, the kind of light-hearted, relaxed, casual way into something that is vitally important.”

“I find that once people open up, it’s an amazing experience every time, like the trust, the sharing that is happening, is holy ground for me to walk with people in that space. And I think it is important to offer those spaces because there is a need for it.”

It brings together people with different backgrounds and experiences

“We had people come because they were inquisitive. We had people come because they wanted to share and learn and express that they wanted a legacy. We had people come that had had loss. We had people come that had near death experiences. We had people come who were going in to be a mortician...And so we had younger, we had older, it was always interesting and I thought that it was a great idea that people could express themselves.”

“There’s a lot of informal information sharing that goes on. We have a regular that is dying from a rare form of brain cancer. And she and her husband have this amazing relationship. And they’re very, very chatty and open...And then, at our last session, we had a lady whose son has been in palliative care since he was born pretty much, now he’s 13. So people come with their own stories.”





What are the Limitations of the Death Cafe Format?

One person may dominate the conversation

“There were people domineering, you know dominating the conversation. And as facilitators we did our best, without calling people out, to try to give people the opportunity to move tables, that kind of thing. But if you've got somebody who needs to tell their story, they're not letting go of that story, we want to give them that chance but it's not the right place.”

The people most likely to attend may be those who need it the least

“I feel like people who attend Death Cafe are the converted. We need to reach the people who aren't comfortable talking about death.”

Not meeting the needs of participants

“There often is a yearning for something else. But the purpose of the Death Cafe is simply the conversation in the evening.”

“So the openness was a strength. But it was also a weakness, because the looseness of it, all the people were starving, they were literally starving for the next step, or something that they could carry on this process with. And as an organizer, we were...always scrambling, and there was no support.”

“So we do learn, I think, a lot about peoples' needs and desires and loneliness and what they're missing in this life. And in the Death Cafe we meet part of that, but it's only part of it. It's an important part, but it's only a small part really.”





What Needs Do You Identify in Alberta?

Informational Needs

“The biggest thing we got back on the feedback forms was ‘I was hoping to get more information’.”

“The difference between all the documents, the goals of care, the personal directive, the power of attorney, all of that. That’s a huge need for everybody.”

“I’ve experienced that with a lot of the groups we’ve had, there are people there looking for...grief counselling, wills, what to do with their mother, homecare, all kinds of things.”

Grief Support

“A Death Cafe really wasn’t a safe place for people who are actively grieving or are palliative. It’s not the right format for them, the group-directed conversation with people who are either inexperienced, or who cannot support the needs. It’s not right for them.”

“What I hear from attendees is, ‘I don’t know how to talk to someone who’s just lost someone’.”

Knowing How to Initiate Conversations

“One thing that people are really, really looking for, and they’re hoping that Death Cafe is going to help them, is ways to approach to have those important conversations. And then educating people on how to support others who are grieving. What I hear from attendees is, I’m here because everybody’s...you know.... I’ve got these awkward silences or people clam up when I’m around or that kind of thing. And the other side of that is, I don’t know how to talk to someone who’s just lost someone.”





Is There a Role for Death Cafe in Building Public Awareness of Palliative Care?

Death Cafe is a good place to start

“Death Cafe is a nice conversation opener to get this going.”

“I love what it does as an introductory piece.”

The Death Cafe format can be limiting

“If you’re bringing awareness to palliative care, then you’re going to have some education in there...there’s an education piece to it. So it’s not going to be called a Death Cafe then.”

Consider offering Death Cafes as part of a “suite of resources”

There are a lot of thirsty brains out there that are looking for information and Death Cafe’s not set up to educate people...But it might be nice to have as part of the suite of resources.”





Conclusion

Death Cafe is an innovative model that has rapidly grown in popularity and global reach since its origin more than a decade ago. Many hospice and palliative care organizations have offered Death Cafes as a means of raising awareness of, and prompting conversation about, death and dying. Death Cafes may contribute to greater openness to public education about palliative care and greater receptivity to receiving palliative care by increasing comfort talking about death and dying.

Death Cafes have attracted hundreds of thousands of participants by creating a safe social space for open-ended conversations about death, but they are not without limitations. In the English-speaking world, Death Cafes appear to have reached a limited demographic of participants, but appropriate facilitation, timing and location might encourage more diverse attendance. Effective marketing might also help reach a broader audience. As Facebook is already widely used to promote these events in Alberta, exploration of ways to optimize the use of this platform is advised.

Some facilitators also feel constrained by the Death Cafe format and are seeking ways to provide additional education about topics such as palliative care, advance care planning, grief and funeral planning. By offering Death Cafes alongside other educational resources this constraint might be effectively addressed while conforming with Death Cafe guidelines.





Acknowledgements

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Appendix 2: Survey

Thank you for agreeing to participate in our survey of Death Cafe facilitators in Alberta. This survey consists of three sets of questions that address: (1) your background; (2) the logistics of organizing a Death Cafe; and (3) the format of the Death Cafe(s) you facilitated. This survey will take approximately 15 minutes to complete. At the end of the survey, you will have the option of volunteering your contact information for follow-up. Please note, responses are not required; questions may be left blank if you do not wish to respond.

Background Information

1. What is your age?
 - A. 18 – 29
 - B. 30 – 44
 - C. 45 – 59
 - D. 60 – 74
 - E. 75+

2. What is your gender?
 - A. Female
 - B. Male
 - C. Transgender
 - D. Non-binary
 - E. Other

3. What is your ethnic origin? Select all that apply:
 - A. African
 - B. Asian
 - C. Caribbean
 - D. European
 - E. Indigenous
 - F. Latin, Central or South American
 - G. Middle Eastern

4. What is your professional background?
 - A. Health care
 - B. Social services
 - C. Funeral services
 - D. Faith leader/spiritual care provider
 - E. Other If Other, please specify your professional background:





5. How many Death Cafes have you attended?
 - A. 1 – 5
 - B. 6 – 10
 - C. 11 – 15
 - D. 16 +

6. How many Death Cafes have you facilitated?
 - E. 1 – 5
 - F. 6 – 10
 - G. 11 – 15
 - H. 16 +

7. What is your goal in facilitating Death Cafes?

8. How would you rate your awareness of palliative care?
 - 1 – None
 - 2 – Limited
 - 3 – Some
 - 4 – Good
 - 5 – Excellent

9. Within the past 10 years has someone important to you received palliative care?
Yes/No

Logistics

10. Where did the Death Cafe(s) you facilitated take place? Select all that apply:
 - A. Cafe
 - B. Library
 - C. Online If Online, please specify the platform(s) used:
 - D. Other If Other, please specify location(s):

11. Was the Death Cafe sponsored/hosted by a partner organization? This could include donating space or refreshments or co-organizing the event.
Yes/No If yes, please specify name of sponsoring organization(s):

12. How did you advertise the Death Cafe? Select all that apply.
 - A. Deathcafe.com
 - B. Social media If B: Please specify social media platforms used to advertise:
 - C. Through a business If C: Please specify which business(es) advertised the event:
 - D. Through a community organization If D: Please specify which community organization(s) advertised the event:
 - E. Local news media
 - F. Other If E: Please specify what other channel(s) you used to advertise:





13. Have you advertised every Death Cafe you facilitated on the Death Cafe website?
Yes/No
14. Approximately how many people attended each Death Cafe you facilitated?
 - A. 1 – 5
 - B. 6 – 10
 - C. 11 – 15
 - D. 16 – 20
 - E. 20+
15. Has the COVID-19 pandemic reduced the number of Death Cafes you facilitated?
Yes/No

Format

16. How did you introduce the Death Cafe you facilitated?
17. Did you provide a conversation starter/icebreaker question(s)? Yes/No
If yes, please specify:
18. Did you suggest additional topics for group conversation? Yes/No
If yes, please specify:
19. Did you make any materials available at the Death Cafe? Yes/No
If yes, please specify:
20. To what extent was palliative/end-of-life care a subject of conversation?
 - 1 – Not at all
 - 2 – Rarely
 - 3 – To some extent
 - 4 – Frequently
21. To what extent was advance care planning a subject of conversation?
 - 1 – Not at all
 - 2 – Rarely
 - 3 – To some extent
 - 4 – Frequently
22. Have you facilitated an event similar to a Death Cafe that was advertised under a different name (i.e. Death Chat)?
Yes/No If Yes, please specify name of event:





Follow-up

23. Do you have any additional comments?

Yes/No If Yes: Please share any additional comments:

24. Would you be willing to have a follow-up conversation with a member of our team? Yes/No

If yes, please provide your name (First Last):

If yes, please provide your email address and/or phone number:

25. Would you like to receive information about the results of this survey?

Yes/No

If yes, please provide your email address for notification of survey results:

Thank you for taking the time to complete this survey.

