Death Cafe: Engaging the community with conversations about death

Presenter: Lizzy Miles, MA, MSW, LSW

Learning objectives

Discuss the unique attributes of the death cafe model that help to create community conversations about death and dying.

Utilize findings from death cafe survey results to enhance understanding of community needs.

What is a Death Café?

A Death Café is a pop-up event where people get together to talk about death and have tea and delicious cake.

The objective of Death Café is to ‘increase awareness of death with a view to helping people make the most of their (finite) lives’

Bernard Crettaz

Swiss Sociologist

At death cafe takes place March 23, 2004 in Switzerland

In 2009, after 40 death cafes, Bernard retired to pursue other projects

Cafés mortels: bringing death out of silence is published April 30, 2010 (in French)

Bernard Crettaz

“I am never so in tune with the truth as during one of these soirées. And I have the impression that the assembled company, for a moment, and thanks to death, is born into authenticity.”

First media coverage

November 1, 2010
Death is a taboo subject in France, according to Swiss sociologist and death café pioneer Bernard Crettaz. "French people find it very difficult to talk about death," he said. He says his mission is to liberate death from what he calls "tyrannical secrecy".

Jon Underwood creates deathcafe.com

Wednesday, 22 September 2010
Welcome
This is about death. I'm interested in how we see it, what we're scared of, what we like, what's funny. 'Cos you never know when you're gonna go...

First Death Café in UK

- September 25, 2011
- Hosted by Jon Underwood and Sue Barsky-Reid
- 6 attendees

My discovery of the Death Café

Death Café comes to U.S.

First Death Café in United States

- July 19, 2012
- Columbus, OH
- 30+ RSVP
- 13 attendees

Death Café Trivia: The next day everyone in the country was talking about death because of the Aurora, Colorado movie theater shooting.

The role of media in the movement

Pros
- 99% positive
- Boosts attendance at individual cafes
- Inspires other cities to host
- Most likely for first in city

Challenges
- Articles that leave out history
- Journalists that do not fact check
- Events called "Death Café" that are not authentic
- Hosts that use media to promote own businesses
Key media dates in the first 3 years

<table>
<thead>
<tr>
<th>Date</th>
<th>Publication</th>
<th>Title</th>
</tr>
</thead>
<tbody>
<tr>
<td>8/2012</td>
<td>The Independent</td>
<td>The Death Cafe Movement: Tea and Mortality</td>
</tr>
<tr>
<td>12/2012</td>
<td>Times Colonist</td>
<td>Mortality on the Menu</td>
</tr>
<tr>
<td>2/2013</td>
<td>Huffington Post</td>
<td>Death Cafe Goes: A Place to Discuss, Learn about End of Life</td>
</tr>
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<td>3/2013</td>
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<td>Calgary's First Death Cafe Hopes to Bring Taboo Subject out Where It Belongs</td>
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<td>4/2013</td>
<td>NPR</td>
<td>Death Cafes Breathe Life Into Conversations about Dying</td>
</tr>
<tr>
<td>4/2013</td>
<td>USA Today</td>
<td>Death Cafes Normalize a Difficult, and Morbid, Topic</td>
</tr>
<tr>
<td>6/2013</td>
<td>Los Angeles Times</td>
<td>Death Cafe: Normalizing Mortality</td>
</tr>
<tr>
<td>7/2013</td>
<td>New York Times</td>
<td>Tea, Two Sugars, and Death: Café Groups Ponder the End</td>
</tr>
<tr>
<td>8/2013</td>
<td>USA Today</td>
<td>Death Cafes: Growing Popularity</td>
</tr>
<tr>
<td>10/2013</td>
<td>Chicago Tribune</td>
<td>Welcome to the Death Cafe</td>
</tr>
<tr>
<td>1/2014</td>
<td>BBC News</td>
<td>At These Coffee Klatches, Death is on the Agenda</td>
</tr>
<tr>
<td>3/2014</td>
<td>The Guardian</td>
<td>What on Earth is a Death Cafe?</td>
</tr>
<tr>
<td>6/2014</td>
<td>South China Morning Post</td>
<td>At Hong Kong's Death Cafe, it is love and life that is on the menu</td>
</tr>
<tr>
<td>7/2014</td>
<td>Toronto Star</td>
<td>At Death Cafe: A Life-Affirming Experience</td>
</tr>
</tbody>
</table>

Death Café expands across the world

Death Café is now in 51 countries

Death Cafe worldwide map
Death Cafés are always offered:

With no intention of leading participants to any particular conclusion, product or course of action
As an open, respectful and confidential space free of discrimination where people can express their views safely
On a not for profit basis, though to be sustainable we try to cover expenses through donations and fundraising
Alongside refreshing drinks and nourishing food – and cake!

What’s different about the Death Café?

It’s NOT
A lecture
A seminar
A way to make money

It’s a movement!

What is a Death Café?

A Death Café is a pop-up event where people get together to talk about death and have tea and delicious cake.

That’s it.

What I know...

Who comes to the Death Café?

| Gender | Age  
<table>
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<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>Female</td>
<td>73%</td>
</tr>
<tr>
<td>Male</td>
<td>27%</td>
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</tbody>
</table>

Survey results from first 9 events in Columbus, Ohio.

Anecdotal conversations with other hosts reveal similarities

How would you describe your faith/religion/belief system?

A work in progress, agnostic, agnostic but experiencing my spirituality as a welcoming, thinking, Mystery-centered religious Christian, Mystical spiritual Catholic, new age spiritual, not sure since first son 1983. Not sure; still working to figure out, open, ordained Unitarian Universalist minister, Universal love
What do attendees talk about?

Death Café Hong Kong, June 14, 2014

Words used to describe the events

Word art from PDX Death Cafe

Survey Results – High points

Survey count = 112 from 9 Death Café events in Columbus, Ohio 7/2012-4/2013

<table>
<thead>
<tr>
<th>Survey Item</th>
<th>Agree or Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>The facilitators treated me with respect</td>
<td>100%</td>
</tr>
<tr>
<td>The facilitators were caring</td>
<td>99%</td>
</tr>
<tr>
<td>Overall I was satisfied with the facilitator interaction</td>
<td>99%</td>
</tr>
<tr>
<td>The facilitators created a safe environment for discussion*</td>
<td>98%</td>
</tr>
<tr>
<td>Overall I was satisfied with the event</td>
<td>97%</td>
</tr>
<tr>
<td>The structure of the event was conducive to discussion</td>
<td>95%</td>
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<tr>
<td>I felt comfortable sharing my thoughts and feelings about death</td>
<td>95%</td>
</tr>
<tr>
<td>* Most highly correlated with overall satisfaction with facilitator</td>
<td></td>
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</tbody>
</table>

Survey Results – Surprises

<table>
<thead>
<tr>
<th>Survey Item</th>
<th>Agree or Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel more comfortable talking about death and dying now</td>
<td>51%</td>
</tr>
<tr>
<td>My perspective on death and dying has changed as a result of my participation in this event.</td>
<td>28%</td>
</tr>
<tr>
<td>And yet…</td>
<td></td>
</tr>
<tr>
<td>It was helpful for me to meet people with different viewpoints</td>
<td>91%</td>
</tr>
<tr>
<td>I would recommend the death café event to my friends and family</td>
<td>92%</td>
</tr>
<tr>
<td>I would consider attending a future Death Café event</td>
<td>94%</td>
</tr>
</tbody>
</table>
Survey Results – Palliative nursing students

<table>
<thead>
<tr>
<th>Survey Item</th>
<th>Agree or Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel more comfortable talking about death and dying now.</td>
<td>Palliative Nursing Students 92%</td>
</tr>
<tr>
<td>My perspective on death and dying has changed as a result of my participation in this event.</td>
<td>Palliative Nursing Students 55%</td>
</tr>
</tbody>
</table>

Death Café comments

“Loved this! Sometimes I think it’s easier to talk about this topic with complete strangers, which I think can help open the door to talk about it with family and friends. I loved hearing everyone’s views and ideas about death - I heard a lot of things I never considered before. Really gets you thinking, which I think is really the point. Thank you!”

“Talking about death and dying is eye opening and healthy. I’ll forget I’m going to die sometimes, it’s good to be reminded.”

“Absolutely a great experience. I was impressed with the richness, quality, and sincerity of the other participants. Conversation is fluid & free flowing & yet respectful & productive.”

Personal Observations

☐ Some people will refuse to talk about death until the day they die.
☐ Some people want to talk so much that they will drive for hours and/or across state lines.
☐ Death Café fulfills an unmet need for ‘death’ workers: hospice, funeral home and medical professionals.
☐ If we allow attendees to pick the topics, the conversation is richer and more varied than we could ever imagine.

Best Practices – The event

☐ No cost
☐ Open to the community
☐ Free from ideology or agenda
☐ Not a support group
☐ Held in a safe environment
☐ Food (tea & cake or more) provided for free or available for purchase
☐ Over 18
☐ RSVP or Not?
Best Practices - Location

- Private room
- Ample parking
- Easily accessible
- Flexible for small group and large group discussion
- "Neutral" place

Best Practices - Facilitation

- Facilitators as "hosts"
- Two people
- No "agenda"
- NO SALES
- Keep facilitator talking to a bare minimum
- Be recognizable
- Rotate among groups
- Clinical background helps

Best Practices - Structure

- Establish ground rules of respecting differences
- Small group discussion
- Rotate groups
- Be flexible and responsive to "vibe"
- 1.5 – 2 hours

Getting started!!

- Download/read guide to running a Death Café from http://deathcafe.com/how/
- Make sure you agree to all guidelines
- Find a location
- Find a co-host
- Pick a date
- Start promoting!

The official Death Café logo

- Some cities design their own logo
- No merchandising of any kind with Death Café name

Best Practices – Promotion

- Get event listed on deathcafe.com
- Word of mouth
- Flyers
- Connect with other Death Café hosts
- Social media – Facebook/twitter/Google+
- Help
- Traditional newspaper listing
- Community newspaper
- Email lists
- Universities
- Memes
- Press release
- Meetup.com (not recommended, but used by some)
Sample Flyers

Be creative but be sure to adhere to guidelines of Death Café. Death Café should be the main focus of the flyer.

Final Fling hosted the first Death Café in Scotland
Artist: Jack Thompson
http://blog.finalfling.com/10—facts-death-cafe/

LGBT Death Café

- Format same as original Death Café
- Need at least one clinician
- Connect with local LGBT community center
- Open to all, regardless of identity

Death Cafés for healthcare professionals

There have been some cases where hosts have set up Death Cafés in hospital/medical environments
All Death Cafés are open to health care professionals, but some may be reluctant to attend a regular event as a “professional”

- Format same as original Death Café
- Extra emphasis on no marketing
- Direction to attendees to talk about personal and not tell patient stories
- If attendees are co-workers, there may be some difficulty in opening up
- Attendance should always be optional

Death Cafés in long term care facilities

- Format same as original Death Café
- Table rotation may be difficult due to assistive devices
- May want to do large group discussion
- Use microphone for hearing impaired
- Host may need to be more involved with facilitating conversation
- Should still be open to community

Photo courtesy of Karen Van Dyke
Death Café San Diego
Death Cafés in college classrooms

- Format same as original Death Café
- Students should be informed ahead of time
- Table rotation may be difficult due to room setup
- Use random seat assignment to separate students who are friends
- Allow time for processing afterwards

Virtual Death Cafes

- Held via conference call line
- Participants should say their name before they speak
- Instruct participants to mute phone when they’re not talking
- Facilitator may want to write down participant names and be inclusive of attendees since there are no visual clues
- Late arrivals may need instructions and will need them again

Tips via Merilynne Rush, host of Ann Arbor Death Café and Dr. Karen Wyatt, End-of-Life University

Connect with Death Café community

- Grassroots movement – informal connection
- Death Café hosts are from all walks of life with one similarity: an interest in promoting healthy discussion of death and dying in the community
- Some cities have multiple hosts. That’s okay! No need to cohost, but helpful to coordinate timing of events.
- Many Death Cafés have Facebook Pages (Not required)
- Some hosts have Twitter accounts under Death Café name (not recommended) or use personal Twitter to promote
- Ask questions at http://deathcafe.com/gallery/practitioners/
- Feel free to email me with questions! lizymiles@gmail.com

In Memory of Jon Underwood

1972-2017
Death Café: Engaging the community with conversations about death

*Best Practices Handout*

**Basic Principles from deathcafe.com:**

Our principles are that Death Cafes are always offered:

- With no intention of leading participants to any conclusion, product or course of action.
- As an open, respectful and confidential space where people can express their views safely.
- On a not for profit basis.
- Alongside refreshing drinks and nourishing food – and cake!

To learn more on how to host your own Death Café please go to [http://deathcafe.com/how/](http://deathcafe.com/how/)

**The event**

- No cost to attendees (donations can be accepted but should not be required)
- Open to the community
- Free from ideology or agenda
  - No set topics to discuss
  - No guest speakers
  - No business promotion
- Not a support group
- Held in a safe environment (accessible to all)
- Food (tea & cake or more) provided for free or available for purchase
- Over 18
- RSVP or not?

<table>
<thead>
<tr>
<th>Advantages to RSVP</th>
<th>Disadvantages to RSVP</th>
</tr>
</thead>
<tbody>
<tr>
<td>Get an idea of how many are coming</td>
<td>Free event may mean you could still have no-shows/cancellations</td>
</tr>
<tr>
<td>Can pre-screen</td>
<td>Individuals are better at deciding for themselves whether it is right format for them</td>
</tr>
<tr>
<td>Asks for commitment in advance</td>
<td>Could reduce attendance</td>
</tr>
<tr>
<td>Food planning is easier</td>
<td>People don’t come to Death Café for food; They are there for conversation, less is more.</td>
</tr>
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**Location**

- Private room (for confidentiality and intimacy)
- Ample parking
- Easily accessible
- Flexible for small group and large group discussion
- “Neutral” place (comfortable and relaxed setting, easily accessible to the community and no promoting of anything.)

**Facilitation**

- Facilitators as “hosts”
- Two people (or one person per 12 attendees)
- No “agenda” and absolutely NO SALES
- Keep facilitator talking to a bare minimum
- Be recognizable
- Rotate among groups
- Clinical background helps; not required (good to have a list of community referrals available if needed)
Structure

- Review brief history of Death Café (available on Deathcafe.com)
- Review Death Café guidelines to the group
- Establish ground rules of respecting differences
- Small group discussion works best as it allows for introverts space to talk
- People that come together should sit in different groups
- Rotate groups so attendees get to talk to more people (get more diverse conversations)
- Be flexible and responsive to “vibe”
- 1.5 – 2 hours (most are 2 hours)

Getting started

- Download/read guide to running a Death Café from http://deathcafe.com/how/
- Make sure you agree to all Guidelines (which includes posting your Death Café on deathcafe.com)
- Find a location
- Pick a date
- Start promoting!

Ways to Promote

*Note: how you promote affects who comes. Death Café is popular with older adults IF they know about it. Don’t rely only on social media*

- Get event listed on deathcafe.com
- Word of mouth
- Flyers
- Connect with other Death Café hosts
- Social media – Facebook/Twitter/Google+
- Yelp
- Traditional newspaper listing
- Community newspaper
- Email lists
- Universities
- Memes
- Press release
- Meetup.com (not recommended, but used by some)

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