

Grief and Bereavement

A National Grief and Bereavement Day Tribute



Date: December 19th, 2022

Presenters: Christopher Klinger and Katt Brooks

Host: Holly Finn, PMP

Territorial Honouring

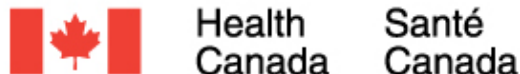


The Palliative Care ECHO Project

The Palliative Care ECHO Project is a 5-year national initiative to cultivate communities of practice and establish continuous professional development among health care providers across Canada who care for patients with life-limiting illness.

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The Palliative Care ECHO Project is supported by a financial contribution from Health Canada. The views expressed herein do not necessarily represent the views of Health Canada.



LEAP Core

- Interprofessional course that focuses on the essential competencies to provide a palliative care approach.
- Taught by local experts who are experienced palliative care clinicians and educators.
- Delivered online or in-person.
- Ideal for any health care professional (e.g., physician, nurse, pharmacist, social worker, etc.) who provides care for patients with life-threatening and progressive life-limiting illnesses.
- Accredited by CFPC and Royal College.



Learn more about the course and topics covered by visiting

www.pallium.ca/course/leap-core

Introductions

Host

Holly Finn, PMP

Senior Manager, Program Delivery, Pallium Canada

Presenters

Christopher Klinger, PhD

Assistant Professor (Part-Time), McMaster University, Department of Family Medicine

Research Scientist, Pallium Canada

Co-Chair, Quality End-of-Life Care Coalition of Canada, Research and Knowledge Translation Committee

Kathryn (Katt) Brooks

Registered Recreational Therapist and Holistic Grief Coach

Conflict of Interest

Pallium Canada

- Non-profit
- Partially funded through a contribution by Health Canada
- Generates funds to support operations and R&D from course registration fees and sales of the Pallium Palliative Pocketbook

Host/Presenter

- Holly Finn: Senior Manager of Program Delivery, Pallium Canada
- Christopher Klinger: Research Scientist, Pallium Canada; Grants from funding organizations such as the Pan-Canadian Palliative Care Research Collaborative (PCPCRC)
- Kathryn Brooks: Nothing to disclose

Welcome and Reminders











- For comments, please use the chat function
- For questions, please use the Q&A function, these questions will be addressed at the end of the presentations
- This session is being recorded—this recording and slide deck will be emailed to registrants within the next week

Grief and Bereavement

Compassion Exercise



Compassion vs Empathy

Compassion	VS	Empathy
 <p>Sympathetic feeling and concern for a person who is suffering</p>		 <p>An ability to understand & feel exactly what the other person is suffering</p>
 <p>A feeling of pity, concern, and sympathy</p>		 <p>A feeling of understanding</p>
 <p>Implies that the compassionate person will help</p>		 <p>Doesn't mean that empathetic person will help</p>
 <p>Positive feelings like love</p>		 <p>Mostly negative like stress</p>
 <p>"I see your pain. Please let me know how can I help?"</p>		 <p>"I understand and see your pain"</p>

Grief

Grief

Grief is a word that we use to explain a complex set of emotions that we experience after loss. It is the emotions sensations and feelings that overcome us after loss. Grief is everything we think and feel after we experience a loss. Grief is a natural and necessary experience in life.

- Thoughts
- Feelings
- Physical sensations
- Unexpected behaviours

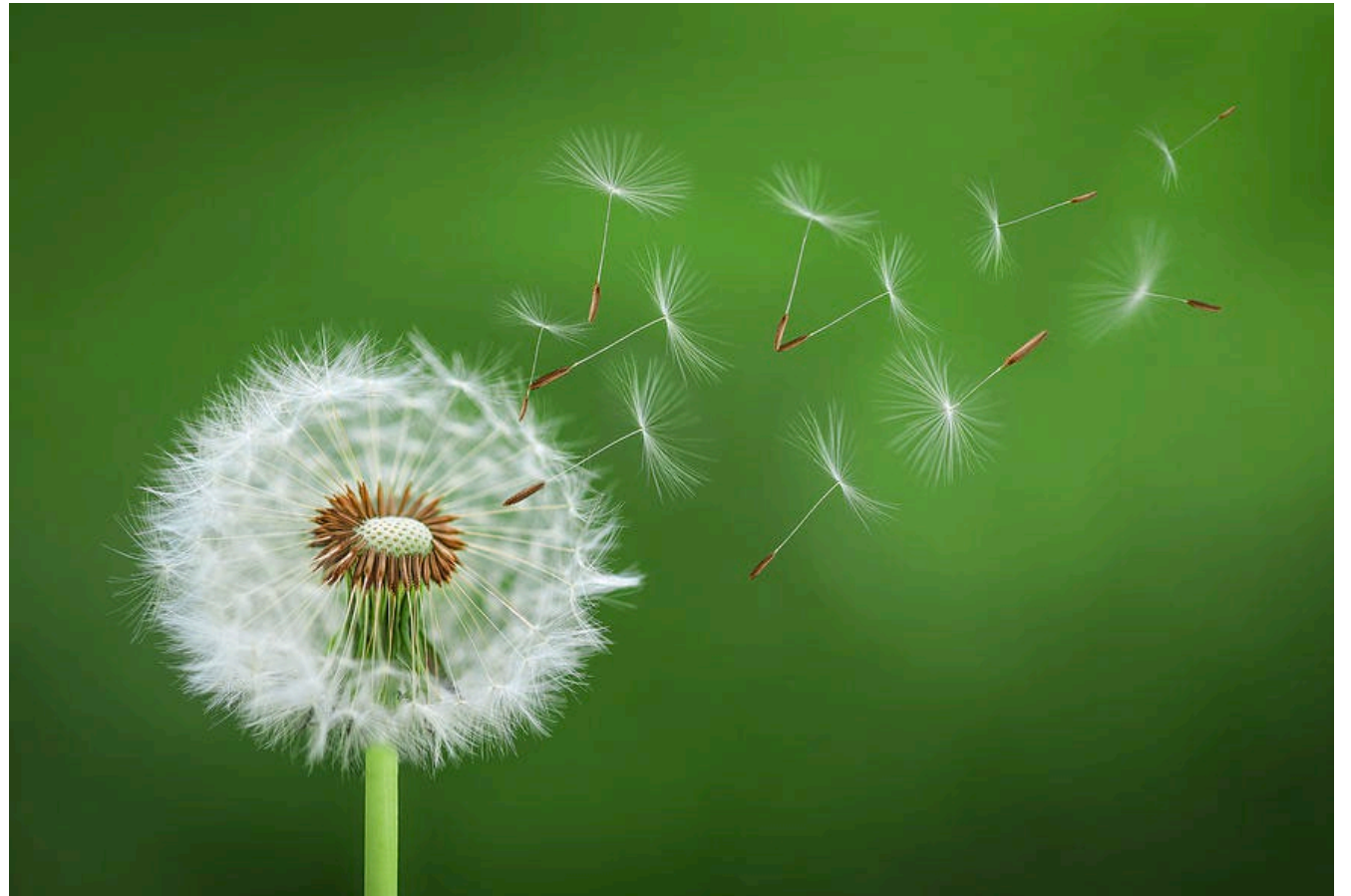
Types of Loss

- Loss of job
- Loss of relationship
- Loss of ability
- Loss of health
- Loss of finances
- Death of a person



Secondary Losses

- Loss of community
- Shift in relationships
- Loss of hopes for the future
- Resentment for the past
- Loss of role identity
- Loss of ability



Bereavement

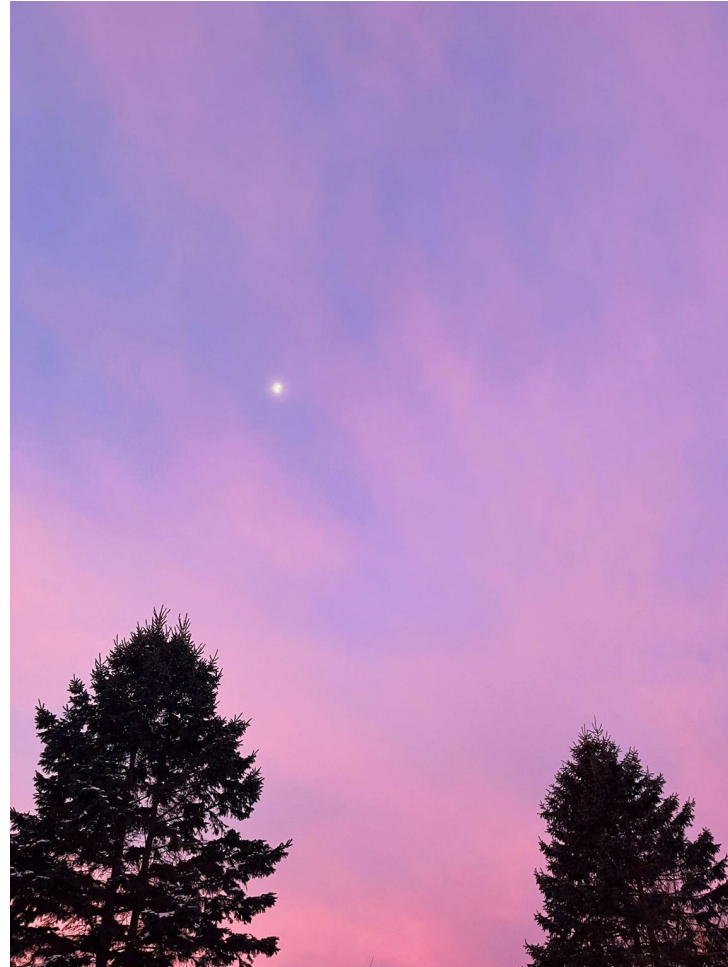
Photovoice



He was, and still is my sun



This Is My Journey



Grief is exhausting



Interventions for Grieving and Bereaved Informal Caregivers: A Scoping Review of the Canadian Literature

Journal of Palliative Care

1-10

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Quality End-of-Life Care
Coalition of Canada
La Coalition pour des soins
de fin de vie de qualité du Canada

Overview

- Background
- Methods
- Results
- Discussion
- Conclusion
- Questions and Answers



Background

Informal caregivers play an essential role as part of the interdisciplinary care team.

- Over **3 million Canadians** provide informal hospice palliative care.
- Dual role of caregiver and family/friend makes grief and bereavement experiences unique.
- Grief vs. bereavement.

Informal Caregivers:

Any family member or friend who provides physical and/or psychosocial care.



Background

Informal caregivers experience grief and bereavement.

- Evidence suggests informal caregivers experience higher levels of depression than non-caregivers.
- Limited understanding of grief and bereavement.
- Grief is a risk factor for elevated health risks and psychiatric disorders.
- ICD 11: Prolonged grief disorder (PGD).



Aim: Understand what interventions currently exist to improve grief and bereavement in informal caregivers.

Methods

Arksey and O'Malley's Framework for Scoping Reviews:

1

Identifying the Research Question

2

Identifying Relevant Studies

3

Study Selection

4

Charting the Data

5

Collating, Summarizing and Reporting the Results

Methods

Step #1: Identifying the Research Question

“What interventions exist in Canada to support grieving and bereaved caregivers of older adults/geriatric patients in (hospice) palliative care?”

Secondary Research Questions:

- Who can benefit from formal grief and bereavement care?
- What is the efficacy of these interventions?
- Are there differences in the effect of interventions for those with ‘normal’ grief, those at risk for complications, and those with complicated (prolonged) grief?
- When should bereavement care be offered?
- Who should provide grief and bereavement services/interventions?
- What services should be offered for grief and bereavement?
- What do bereaved persons find useful/helpful?

Methods

Step #2: Identifying Research Studies

Scholarly Articles

- Ageline
- Applied Social Science Index and Abstracts (ASSIA)
- Cumulated Index to Nursing and Allied Health Literature (CINAHL)
- Cochrane Library
- OVID Embase
- OVID Medline
- OVID PsycInfo
- Proquest Sociological Abstracts
- Scopus

Grey Literature

- Proquest Dissertation & Theses Database
- Canadian Hospice Palliative Care Association
- Canadian Cancer Society
- Canadian Virtual Hospice
- Family Caregivers of British Columbia
- Young Carers Program
- Ontario Public Health Library Association

... & Many More!

Methods

Step #2: Identifying Research Studies (Continued)

Concept #1

Palliative Care

- Hospice Care
- Terminal Care
- End-of-Life Care

Concept #2

Grief and Bereavement

- Mourning
- Loss
- Psychological Distress

Concept #3

Informal Caregivers

- Family
- Sibling(s)
- Relative(s)

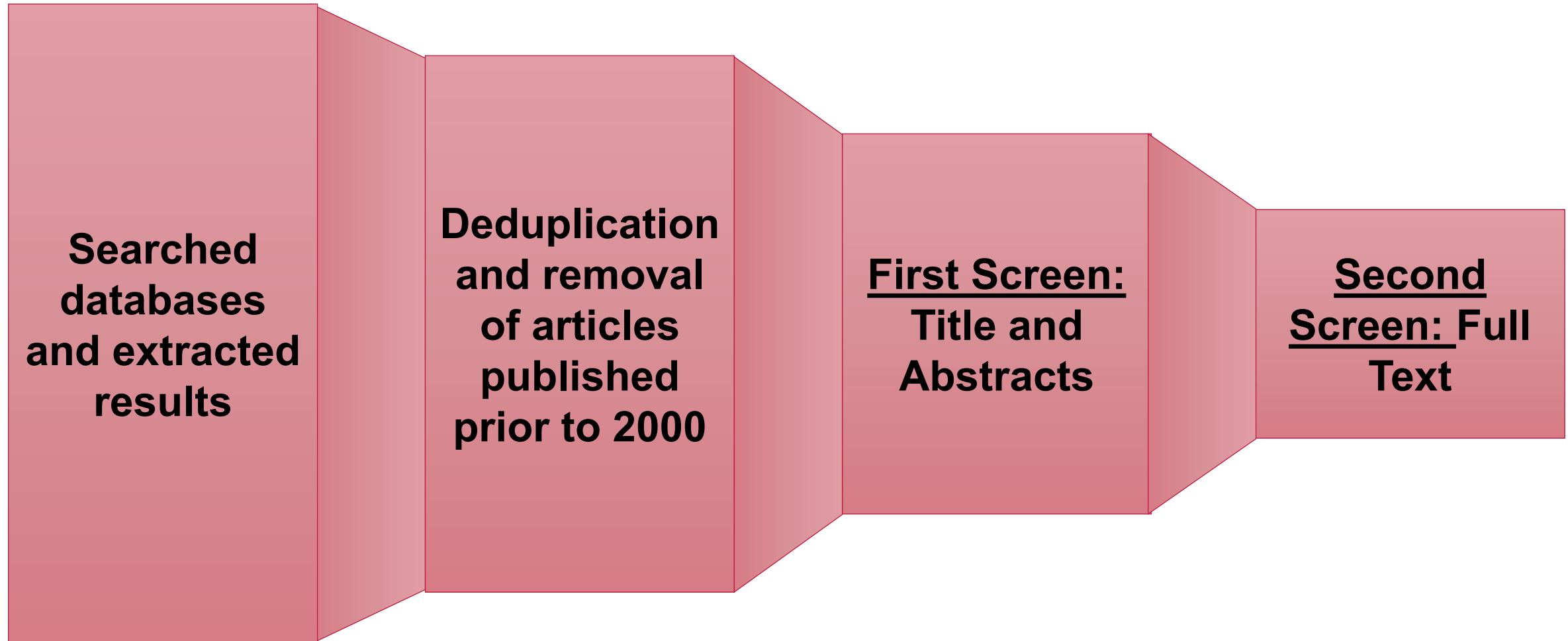
Concept #4

Interventions

- Psychotherapy
- Counseling
- Telemedicine
- Spiritual Care

Methods

Step #3: Study Selection



Methods

Step #3: Study Selection

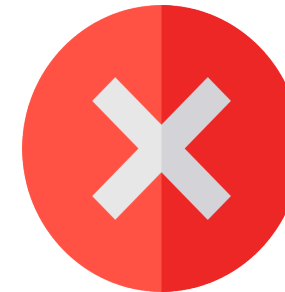
The criteria for inclusion were:

- Published from January 2000 – October 2020
- English language
- Conducted in Canada
- Focused on interventions, strategies, or services offered in geriatric (hospice) palliative/end-of-life care settings to support informal caregivers through bereavement



The criteria for exclusion were:

- Prior to January 2000
- Conducted outside of Canada
- Written in a language other than English
- Did not describe interventions for informal caregivers of geriatric (hospice) palliative/end-of-life care patients experiencing grief or bereavement



Methods

Step #4: Charting the Data

Two independent reviewers completed data extraction to identify several elements of each study.

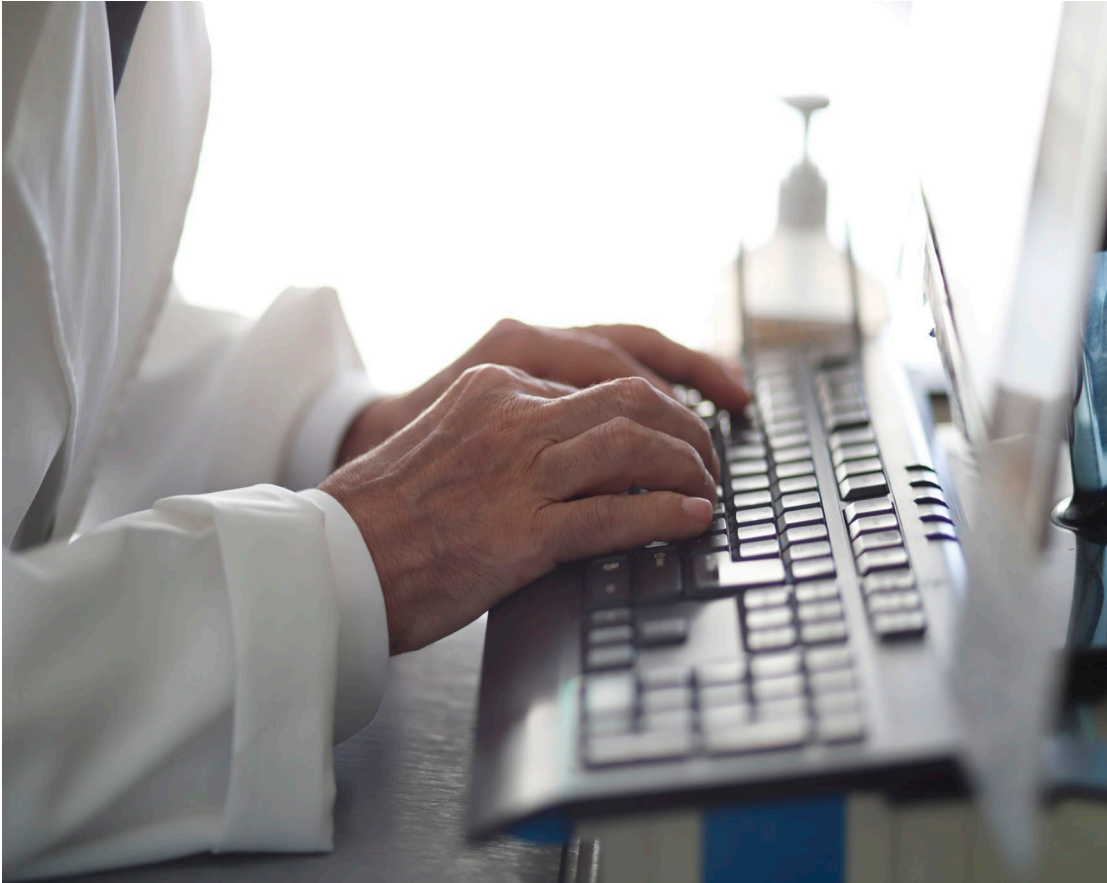
Extracted Data Included

- Purpose
- Sample
- Setting of care
- Study design
- Outcome measures
- Findings
- Themes
- Implications

Themes and subthemes were iterated upon before, during and after the charting process through whole team discussions.

Methods

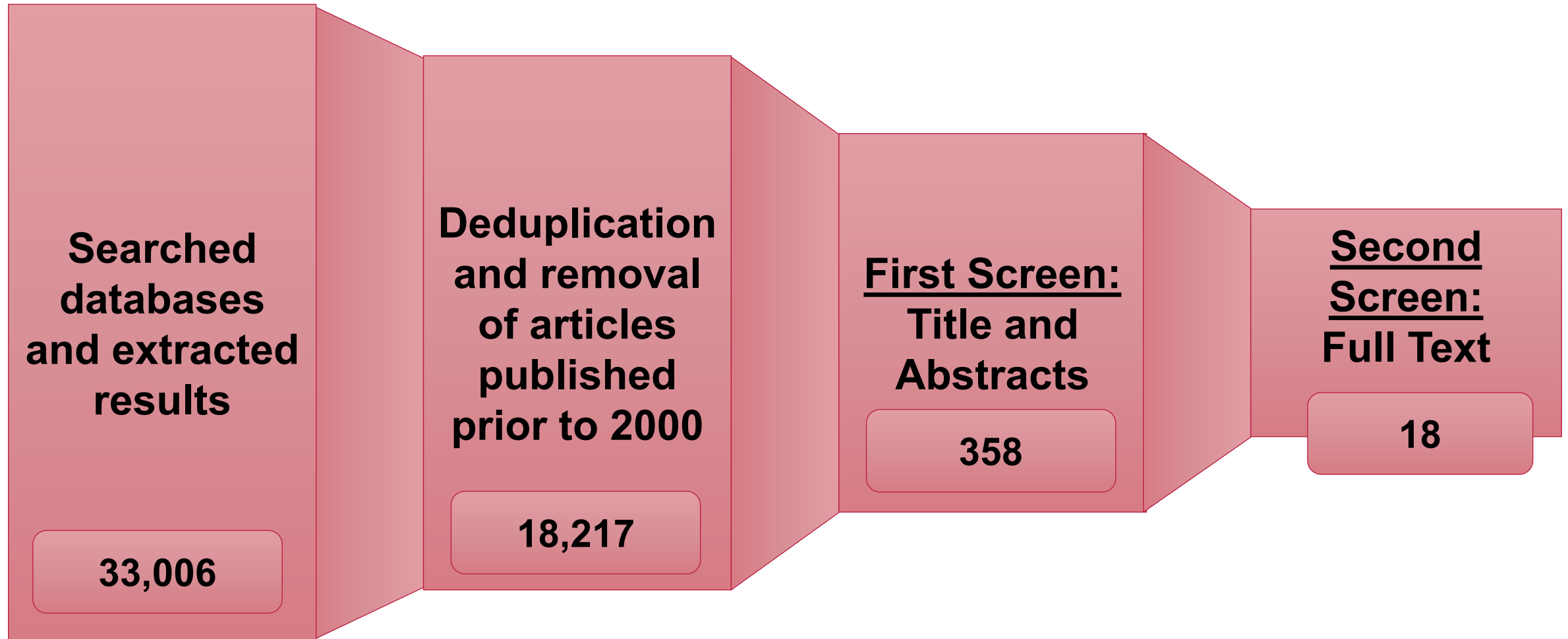
Step #5: Collating, Summarizing, and Reporting the Results



- **No appraisal of the quality** of the evidence was conducted.
- **Final themes were determined** by the team after review of the scholarly and grey literature in the data extraction table.
- Themes that occurred frequently and/or were highly relevant to the overall scoping review were identified via **thematic content analysis** and **cross-referenced with the research questions**.
- Findings were compared with **international literature** and **literature surrounding COVID-19** to offer a **broad and timely perspective**.

Results

After screening, **18 relevant articles** were identified and included.



Results

Three key themes emerged from thematic content analysis:

Classification

What kind of intervention is it?

- Creative
- Psychosocial
- Indirect Comparative Analysis

Format

How is it delivered?

- Delivery Method
- Setting
- Frequency
- Timing

Target

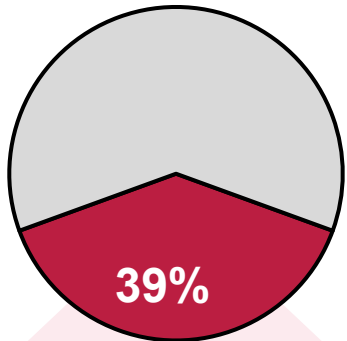
Who is it delivered to?

- Caregivers
- Healthcare Providers
- Volunteers

Results

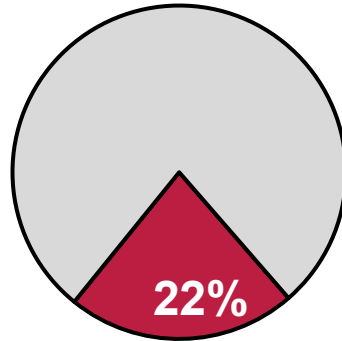
Theme #1: Classification

Creative

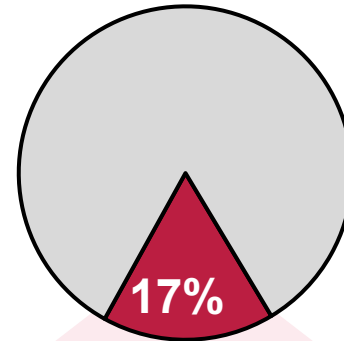


Art Therapy
Music Therapy
Written

Educational

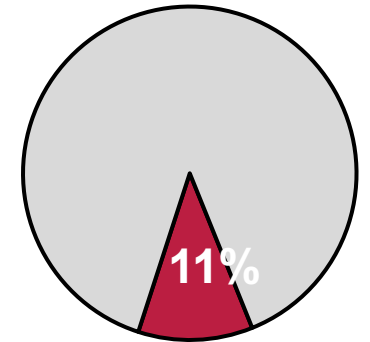


Psychosocial



Spiritual Care
Support Groups

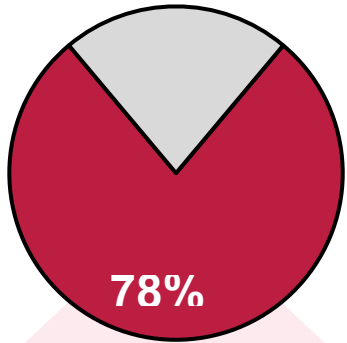
**Indirect
Comparative
Analysis**



Results

Theme #2: Format

Delivery

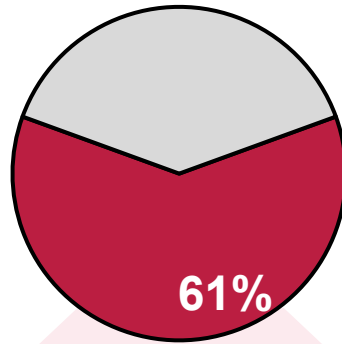


In-Person

Online

Telephone

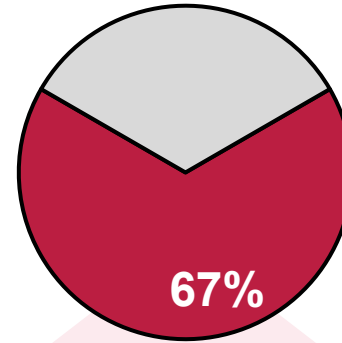
Setting



Care Setting

Home

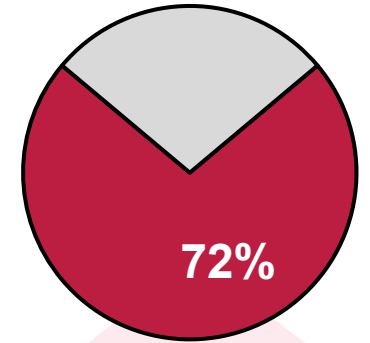
Frequency



One-Time

Ongoing

Timing



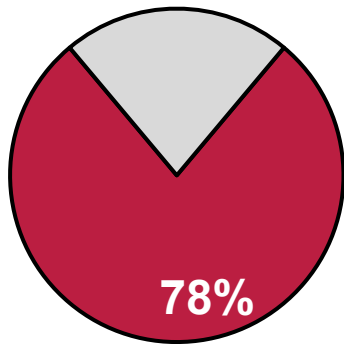
Post-Death

Pre-Death

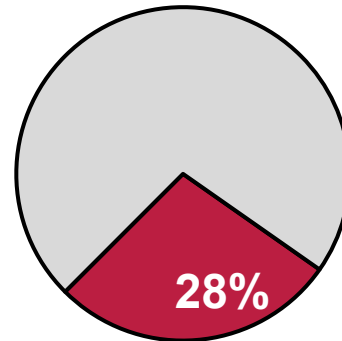
Results

Theme #3: Target

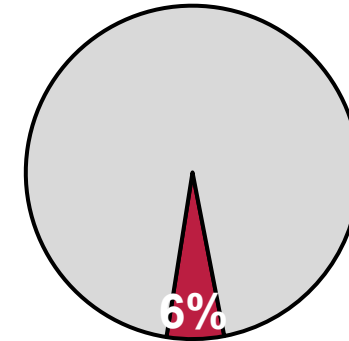
Caregivers



Healthcare Professionals



Volunteers



Discussion

The findings of this scoping review align with international literature:



- Several American studies reported on the **medium of delivery**, including **telehealth** and **online** services.
- Some highlighted the **potential for online delivery** of grief and bereavement services.
- Other international studies included the **gifting of bereavement cards**, and establishment of **compassionate communities**.



Discussion

Implications

Practice

- **Increased clinical attention** to grief and bereavement.
- **Education and training** is needed for diagnosis.
- **Collaborations** between care providers may be beneficial.
- **Consider accessibility** of interventions.

Policy

- Grief and bereavement support should be a **priority for health promotion**.
- Need for **inclusion** of grief and bereavement in all hospice and palliative care settings.
- **Increased funding** for grief and bereavement services.

Research

- Need for **large-scale studies** to establish effectiveness of interventions.
- Development of accurate **screening tools**.
- **Engagement of caregivers** in research can be beneficial for designing interventions.

Discussion

COVID-19 has impacted grief and bereavement care.

- Hospice providers have had to **transition their programming online**.
- The potential for long-term changes to delivery methods must be considered to **increase accessibility** and **reach**.
- The pandemic may result in an **increase in complicated (prolonged) grief**:
 - This is due to patients being separated from caregivers in their final moments.
 - Stripped opportunities for meaningful good-byes by preventing cultural and social rituals associated with grief.



Discussion

Strengths and Limitations

Strengths:

- Exploration of grief and bereavement interventions for informal caregivers offered in (hospice) palliative and end-of-life care settings in the Canadian context
- The use of the Arksey and O'Malley framework allowed for a broad review and synthesis of the literature
- The use of both academic and grey literature enabled the capture of a variety of data sources

Limitations:

- Lack of quality assessment of the included articles
- Inclusion of only English articles, despite Canada being a bilingual country
- Exclusion of articles published prior to the year 2000

Conclusions

- The results show that although there are a diverse set of interventions that have been studied, there is a need for **further evidence** and more robust studies to **evaluate effectiveness**.
- It is necessary for healthcare providers, policy makers, and researchers to acknowledge the importance of providing **evidence-based interventions** for informal caregivers facing grief and bereavement.
- Interdisciplinary collaborations between these individuals will be required to further develop, evaluate, and scale these interventions.

→ [Canadian Grief Alliance](#)



Further Resources:

[MyGrief.ca](#) [KidsGrief.ca](#)  [CANADIAN VirtualHospice](#)

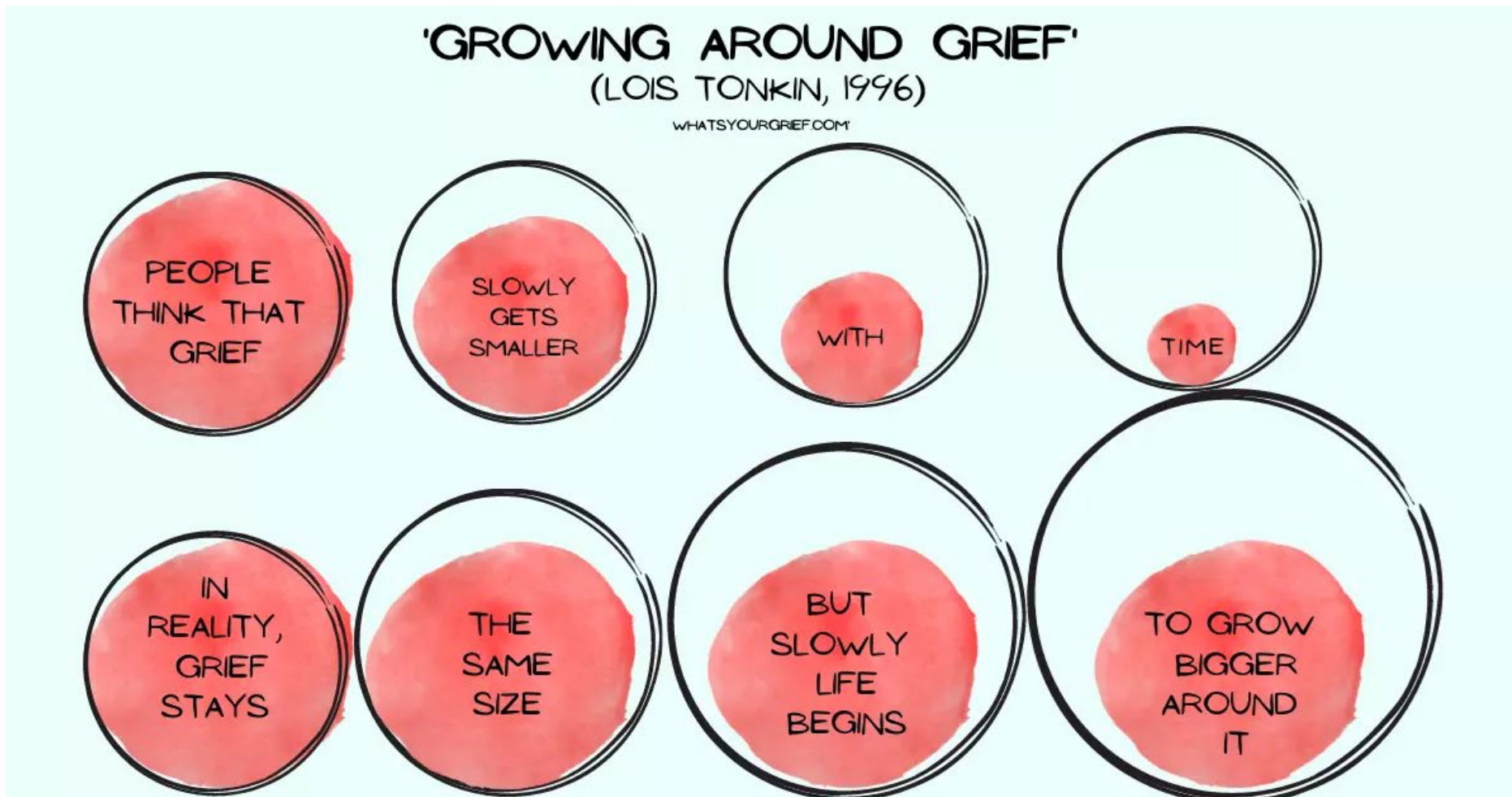
Questions?

Complexities of the Grief experience

Giving In To Grief

What if you just allowed grief to do its very important work in your heart, body, and soul, without trying to hide from it or interfere?

Grief gets smaller over time



We seek connection in our Grief



Fear of vulnerability

- As a society we fear difficult feelings.
- We want to fix someone.
- We fear bringing up a grievance, so we often say nothing at all.
- We suffer in silence.



The Impact of Language

- “Wow you are doing really well”
- “You are so strong”
- “I thought you would be better than this”
- “You can always have another child”
- “Why would you try and work things out?”



Why is it important to communicate with our children?



The Importance of Talking to Our Children

- Our children are specialists in us, intuitive to understand when something is wrong.
- Honesty fosters open communication.
- Increases a child coping skills:
 - Children feel valued and included.
 - Important in building trusting relationships.
- Allows space for Legacy:
 - Child—how they view themselves within the family unit, seen as a sibling.
 - Family—able to create meaning legacy rituals for entire family unit to feel a part.



The Importance of Talking to Our Children

- We are giving our children permission to be a part of the life of the child we lost.
- Open communication of difficult topics normalizes it for children.
- Giving the child permission to grieve with you.



Did you/do you have any fears or worries
about talking to children?

Common worries or fears...

- Will I traumatize my children by telling them ?
- It is meaningful for me to tell my child if they never met the baby? Saw us pregnant?
- Should I wait to tell them when they are older?
- I am so afraid to cry in front of my child, will this affect them negatively?



Communicating with children

- Child appropriate language.
- Be as honest as possible.
 - Name it, knowledge is power.
- Avoid Euphemisms.
 - Inside my heart.
 - Gone to a better place.
 - Passed away.
- Children need us to be blunt and literal with our language.
- Tell what we do know.
- Wondering about what we do not know:
 - How long
 - After life
 - Not knowing humanizing us



Communicating with children

- Be prepared to repeat yourself.
 - Conversations never happen at opportune moments.
- Stick to the same language each time you talk.
- It is okay to not have all the answers,
 - This humanizes us to children.



Common questions...

My child is bringing up death all the time...

My child is saying they feel sad more since we told them...

My child is asking to die and go to heaven...

My child is asking to go to the hospital to see the baby...



Focus of support

- Emotional literacy
- The big W: Worry
- Coping strategies
- Medical education
- Normalization



Emotional literacy

Frustrated

Happy

Guilt

Jealous

Worry

Fear

Confusion

Angry

Embarrassed

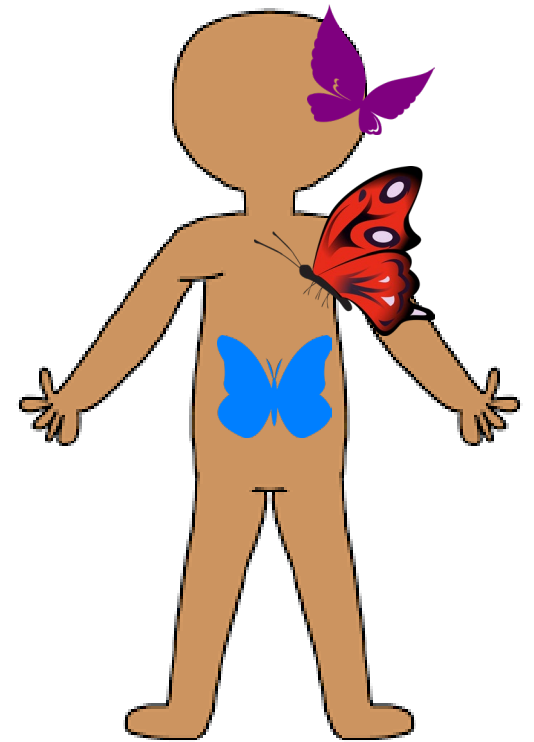
Emotional literacy

- Will likely experience all these emotions.
- We must educate children that feeling all emotions is 100% okay.
- How can we tune into our bodies?



Emotional literacy

- When I feel sad, I feel blue butterflies in my belly.
- When I am worried, I feel purple butterflies in my head.
- When I am angry, I feel red butterflies in my chest.



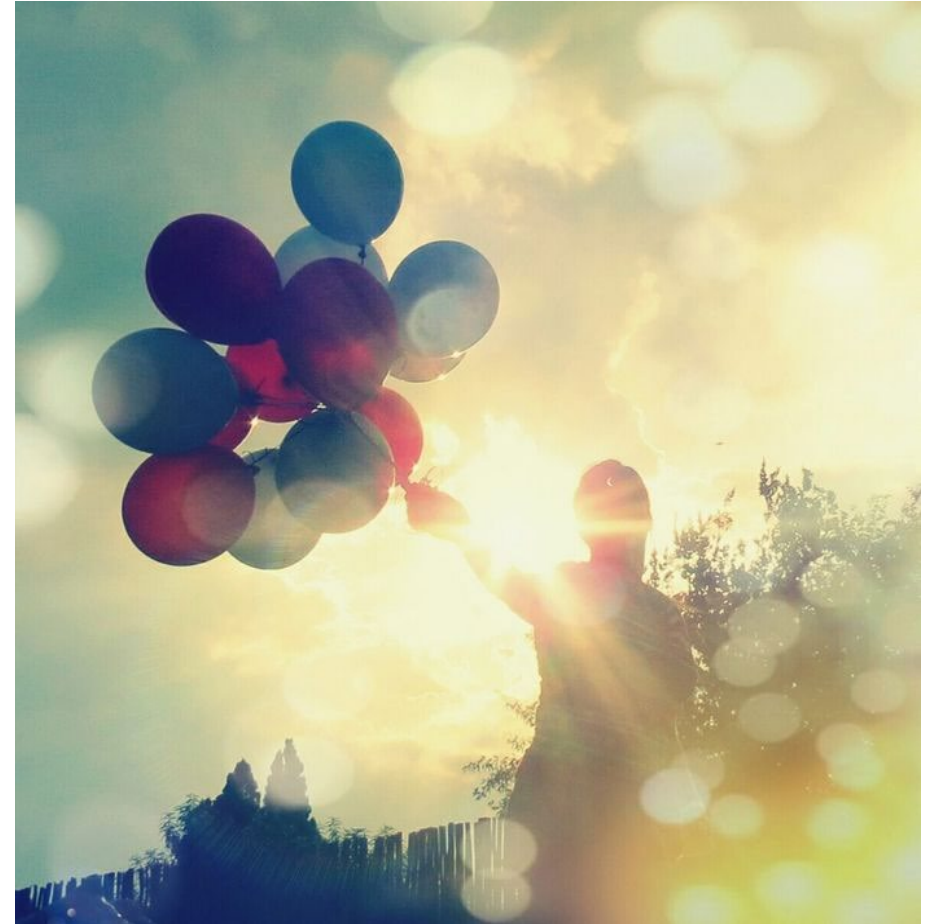
Normalization

Our role as professionals, parents is to children in making some sense of a very difficult experience, support them in normalization.

- Education
- Peer support
- Talking about difficult topics
- Empowering siblings to be the best advocate

Creating memories

- Continue to share stories
- Say your child's name
- Identify family roles (if wished)
- Create accessible remembering space
- Creating the space
 - Sharing your feelings with family members
 - Asking questions..(I notice, I wonder)
- Create rituals and celebrations



Talking about our babies

- Children will love to hear stories of your babies time in your belly
- Tell about the babies personality
- Make connections to their time in your belly
- Tell stories of things you did while baby was in your belly
- Tell about cuddles
- What did baby look like?
- Who did baby look like?
- Who held baby?



Companioning in Grief

- Listen, without trying to fix a person
- Dedicate the time to the person who is grieving
- Promote that their journey is their own
- Focus on grounding and centering your energy to truly show up for person who is grieving
- Let emotions come
- Say the name of the person who died, and share memories.

What does Legacy mean to you in your life,
and the population you serve?

Legacy

“Anything handed down from the past, as from an ancestor or predecessor”

- *Dictionary*

“Legacy is not always tangible or physical, it is emotion and built off of not only memory, but also connection”.

- *Kathryn Brooks*





Q & A

Session Wrap Up

- Thank you for joining us!
- Please fill out the feedback survey following the session—a link has been added into the chat.

Thank You



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