

# HONORING THE VOICES OF BEREAVED CAREGIVERS:

## FINDINGS FROM A METASUMMARY OF QUALITATIVE RESEARCH

*The goal of this research was to explore the qualitative literature about bereaved family caregivers of persons who had received palliative care and ultimately to give them a voice.*

Holtslander, L., Baxter, S., Duggleby, W., Duncan, V., Hudson, P., Peacock, S., Mills, K., Bocking, S., Ogunkorode, A., Dagostari, T.



### CAREGIVER VIDEO LINKS

“Honoring voices after caregiving”

<https://vimeo.com/142840098>

“Honoring voices: walking alongside the caregiver”

<https://vimeo.com/142545652>

“Caregiving 101: Dick Strayer - His story”

<https://vimeo.com/163745672>

“Reinventing a life: Sherill Miller – Her story”

<https://vimeo.com/163953251>



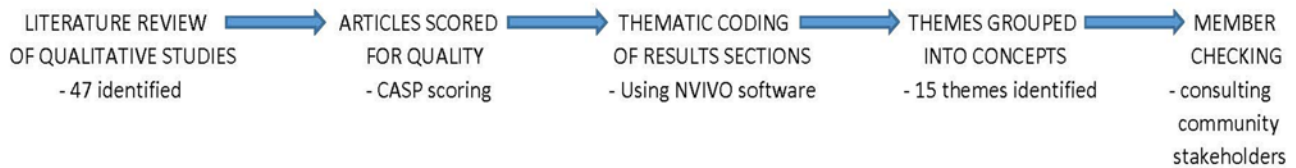
### WHY DO CAREGIVERS NEED A VOICE?

- Family caregivers are the backbone of palliative and end-of-life care in Canada.
- Nearly half of all Canadians will act as family caregivers for their loved ones at some point in their lives.
- Caregiving can be physically and emotionally demanding, and caregivers often face bereavement with exhaustion, few supports, and limited resources. This puts them at risk for complicated grief, depression, or physical illness
- A significant gap exists in end of life policy, supports and services that would promote positive outcomes for this population.



## HOW DID WE GATHER WHAT THEY SAID?

- Sandelowski and Barroso's (2007) Metasummary and Metasynthesis methods were used to integrate the results of qualitative research about the lived-experiences of bereaved family caregivers whose loved ones received palliative care.



## WHAT DID WE FIND?

1. Caregivers reported feeling a range of normal emotions, such as:

- Acceptance & relief
- Sadness & loneliness
- Guilt & regret
- Uncertainty & confusion
- Shock & trauma
- Denial & numbness
- Anger & resentment

**Emotions may change many times in a short period of time.**



2. Caregivers may feel the loss of both their loved one and their role as a caregiver.

**They may find themselves needing to reinvent their lives.**

3. Their grief may be affected by many things: their age, their culture, their gender, the length and intensity of loved one's illness, the quality of health services they received, and their relationship with their loved one

**Grief is different for everyone.**



4. Losing a loved one can bring many changes to aspects of their everyday life, such as:

- Living arrangements
- Relationships
- Finances
- Health

**This adjustment can take a long time.**



## THE KEY MESSAGES FROM OUR RESEARCH:

- The caregiving experiences affect the person during their bereavement
- Every bereavement journey is unique because each journey and relationship is unique
- A variety of supports must be developed and made available to caregivers to meet these unique needs

## WHAT DID WE DO WITH THE RESEARCH FINDINGS?

- The research findings were mobilized through the development of a number of short videos with bereaved caregivers who were willing to share their story.



- The videos highlight stories of 4 caregiver role models who have experienced bereavement and their suggestions for getting through the challenges of grief and loss after caregiving.

