

Key Messages from a Metasummary of Qualitative Research to Honor the Voices of Bereaved Family Caregivers

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INTRODUCTION

- Family caregiving can be physically and emotionally draining, especially in the context of advanced disease, and result in challenges to looking forward during bereavement (Holtslander, et al. 2011)
- Many caregivers will face bereavement exhausted and feeling isolated, and are at risk for prolonged or complicated grief (Stajduhar, et al. 2010)
- Although palliative care guidelines identify the importance of support for family, extending into bereavement, very little is known about their experiences or how to best support them (WHO, CHPCA).
- Furthermore existing literature has not yet been systematically synthesized.

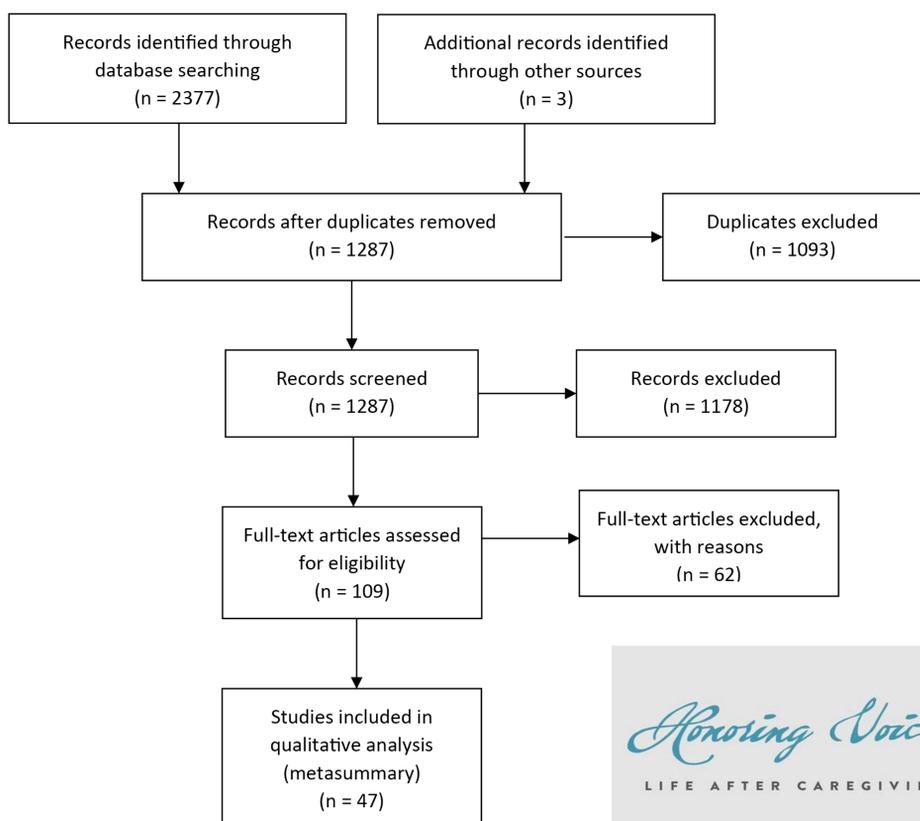
OBJECTIVES

- Complete a metasummary of qualitative research to answer the question: *"What are the bereavement experiences of family caregivers whose loved ones received palliative care?"*
- Identify and expand upon key messages that emerge from the sampled literature, with particular attention to clinical and research implications and knowledge dissemination.
- Produce a series of brief videos centred on the lived experiences of bereaved caregivers to serve as video modelling interventions for this population



METHODS

Using Sandelowski and Barroso's (2007) approach, a metasummary of qualitative research with bereaved caregivers was completed by an interdisciplinary team of international researchers, clinicians, policy-makers, and community members.



A set of key messages and recommendations from the findings was developed and formed the basis of a series of videos that feature participants who were bereaved caregivers.



RESULTS

- Five of the metasummary themes with the largest effect size include:
- Emotional Journeys** describes the wide diversity of emotions that bereaved caregivers reported, including serenity, relief, sadness, guilt and regret
 - Connecting with Life Again: Experiences of Healing Post-Loss** captures experiences that were helpful including receiving support from family, friends and health care professionals and the use of coping strategies
 - Stumbling Blocks: Post-Loss Experiences that Disrupt the Healing Process** include the lack of supports and pressure to "move on"
 - The "Work" after Death: Practical Tasks and Lifestyle Adjustments** describes the challenges of life alone, many losses, and financial stress
 - Performance of a Lifetime: Caregivers' Appraisals of Role and Meaning** involved the need for a new identity and making decisions

KEY MESSAGES INCLUDE THE NEED TO:

- The caregivers' experiences during active caregiving does affect them into bereavement. There is a need to consider the entire caregiving trajectory.** *Caregiver age, length and intensity of loved one's illness, services received, relationship with the patient, among others, are reported as impacting the grief experience either positively or negatively.*
- Each caregiver's experience is unique and there is a need to respect the diversity of each caregiver's experiences.** *Caregivers report a wide range of emotions after losing their loved one, such as overwhelming grief or a "loving sense of relief." Caregivers may face a loss of purpose and meaning.*
- Acknowledge that each person needs different kinds of support** *The need for support is reported extensively, specifically consistent support, support from similar others and opportunities to talk about their losses. Different kinds of supports are needed (e.g. practical and emotional).*

Videos integrated key messages and were found to be meaningful in a public forum (n=75) and a focus group (n=12):

- "Very well done. Very real and honest."
- "I thoroughly enjoyed the "realness" of the films."
- "The focus on the needs and thoughts of the caregiver was a mental and attitudinal shift for me."
- "Some repetition in videos"
- "Some of the text on the screen was difficult to read, or flashed by too quickly"



CONCLUSION

- Qualitative metasummary brought together a diverse body of contemporary research on family caregivers' bereavement.
- The key messages emerging from the metasummary emphasize that a person-centred approach, that attends to individual uniqueness, would best address the needs of caregivers in bereavement.
- Evidence-based video interventions for bereaved caregivers encourage knowledge mobilization and may increase visibility of the needs of this population.
- Future research could focus on: integrating the findings of qualitative and quantitative research in this topic area, on caregiver subgroups that have been under-investigated (e.g. carers of patients with motor neurone disease), or on video role-modeling.

VIDEO INFORMATION

Our videos can be found at the following links:

- "Honoring voices after caregiving" – <https://vimeo.com/142840098>
- "Honoring voices: walking alongside the caregiver" – <https://vimeo.com/142545652>
- "Reinventing a life: Sherrill Miller – Her story" – <https://vimeo.com/163953251>
- "Caregiving 101: Dick Strayer - His story" – <https://vimeo.com/163745672>

