



Canadian Hospice Palliative Care Conference

Congrès canadien de soins palliatifs

Gaps in Hospice Palliative Care Research: A Scoping Review of the Literature

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September 20th, 2019

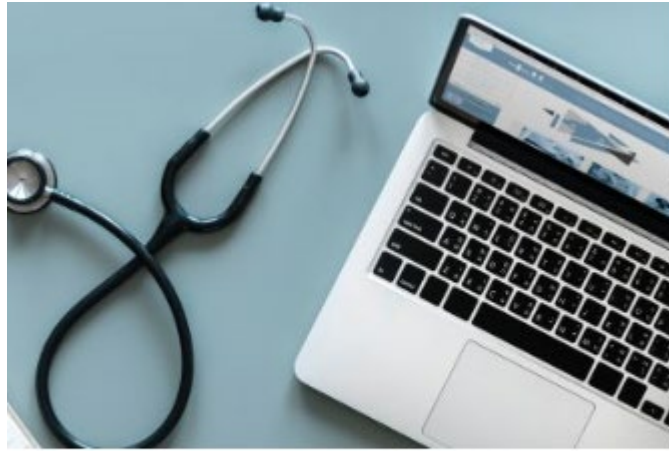


Ottawa, Ontario

Presentation Overview

- Background
- Scoping review methodology
- Gaps in the literature
- Implications for policy, practice and research

Rebecca
Antonacci



Health Studies >



UNIVERSITY OF TORONTO
OISE | ONTARIO INSTITUTE
FOR STUDIES IN EDUCATION

Christopher
Klinger



NICE

National Initiative for the Care of the Elderly

Initiative nationale pour le soin des personnes âgées

We care together

Ensemble pour le bien-être des aînés



Quality End-of-Life

Care Coalition of Canada

La Coalition pour des soins

de fin de vie de qualité du Canada

Faculty/Presenter Disclosure

Disclosure of Commercial Support

Mitigating Bias

Presenter Names: Rebecca Antonacci and Christopher Klinger

Relationships with commercial interests: None

Describe financial support for this program: None

Describe in-kind support for this program: None

Mitigating Bias:

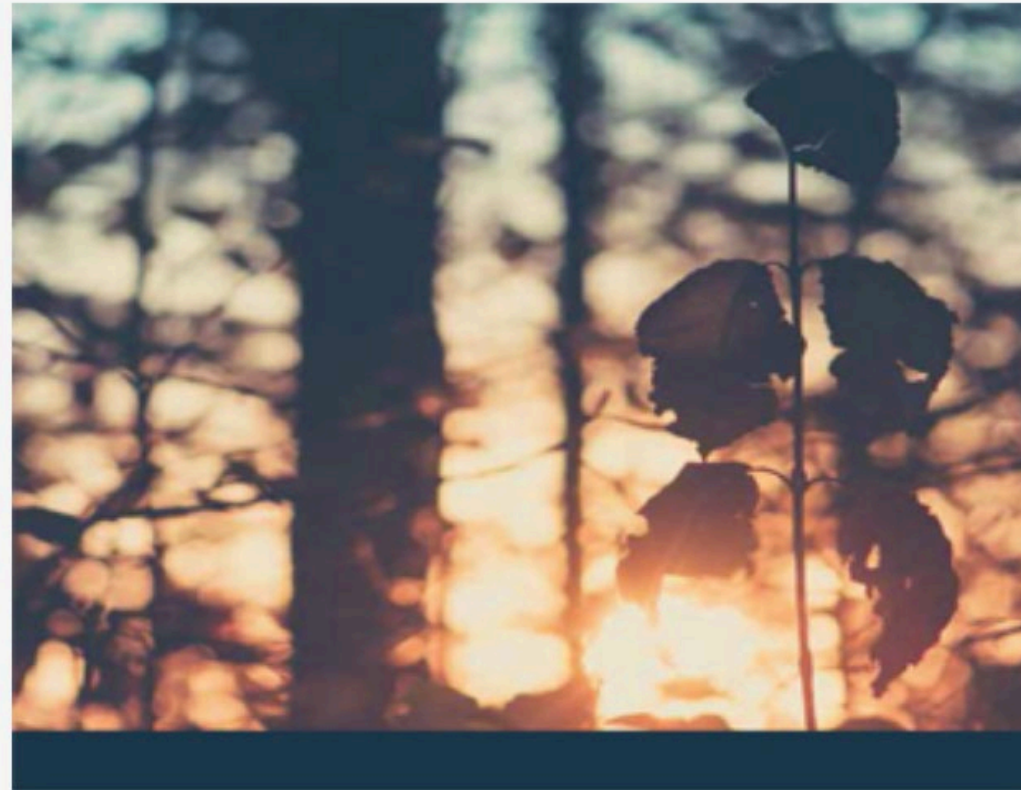
Rebecca Antonacci's conference participation is supported via a free registration from the Canadian Hospice Palliative Care Association for work unrelated to this presentation.

Christopher Klinger is a Member of the Conference Planning Committee, chairs the QELCC's Research and Knowledge Translation Committee and works for Pallium Canada on a new LEAP leadership course.

All abstract submissions to the conference were peer reviewed by two independent reviewers.



Background

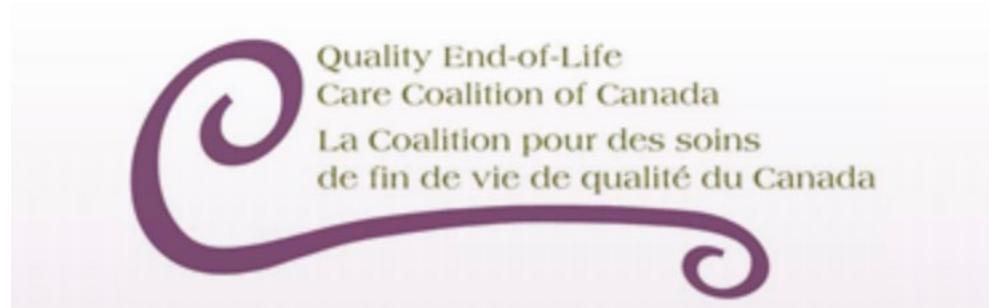


ACTION PLAN ON PALLIATIVE CARE

BUILDING ON THE FRAMEWORK ON PALLIATIVE CARE IN CANADA



CPCA 1999 Report/ QELCCC 2017 Report



Canadian Agenda for Research in Palliative Care

A Report By The

National Research Advisory Committee

Of The

Canadian Palliative Care Association

Palliative Care Research Funding in Canada

An Environmental Scan

Final version - May 2017

Methods

- April 2018-July 2019 a scoping review was conducted based on Arksey and O'Malley's framework
 - Identifying consistencies in the literature
 - Addressing broader research questions

Methods

- Arksey and O'Malley Steps
- 1. Identifying the research question
- 2. Identifying relevant studies
- 3. Study selection
- 4. Charting/collating the data
- 5. Summarizing and Reporting



Scoping review team





Extraction Table

6: Patel MI, Periyakoil VS, Moore D, Nevedal A, Coker TR. Delivering End-of-Life Cancer Care: Perspectives of Providers. Am J Hosp Palliat Care. 2018 Mar;35(3):497-504. doi: 10.1177/1049909117719879. Epub 2017 Jul 10. PubMed PMID: 2869149				y	Y
7: El-Jawahri A, Traeger L, Shin JA, Knight H, Mirabeau-Beale K, Fishbein J, Vandusen HH, Jackson VA, Volandes AE, Temel JS. Qualitative Study of Patients' and Caregivers' Perceptions and Information Preferences About Hospice. J Palliat Med. 2017 Jul;20(7):759-766. doi: 10.1089/jpm.2016.0104. Epub 2017 May 30. PubMed PMID: 28557586; PubMed Central PMCID: PMC5695752.				Y	y



Methods



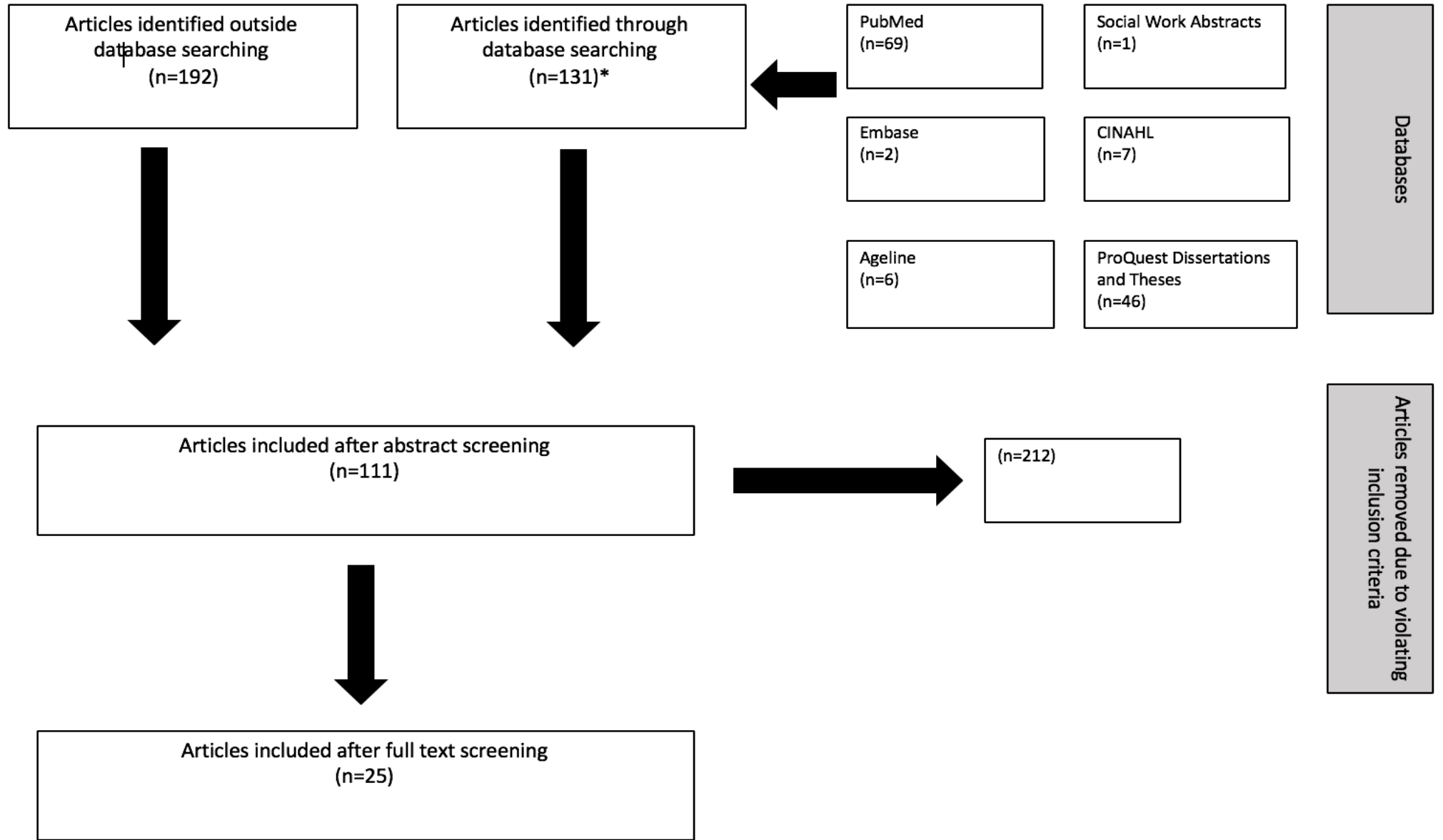
Search Terms

- "Palliative care" AND "Gaps",
- "Palliative care" AND "Research Gaps",
- "Palliative care" AND "Canada",
- "Hospice palliative care" AND "research gaps"

Inclusion Criteria

- Any type of study (RCT, review etc)
- Palliative care
- North America and/or Europe
- 2000-2019
- English
- Referring to research and/or knowledge gaps

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*1 article removed due to inability to retrieve through RACER

Thematic Content Analysis

Themes	Number of Studies With Each Theme	Percentage of themes out of 25
Access to Care	9	36%
Clinical	17	68%
Caregiving	8	32%
Research Methods	14	56%



Access to Care

- 9 articles, 36%
- Focus on acute care
- Studies focused on populations other than older adults
- Not culturally appropriate/sensitive
- Lack of information on cost-effective care
- Understanding the care needs of those who die in other places besides hospitals



Clinical

- 17 papers, 68%
- Development of tools that are culturally appropriate ex:
pain scales in other languages
- Training in healthcare workers
- Tools to address gap in desired decisions and actual
decision making
- Practitioner's understanding of grief and bereavement



Caregiving

- 8 papers, 32%
- Mental health and emotional support
- Identifying populations of caregivers who need support
- Elements of caregivers and caregiving in end-of-life care are assumed rather than directly tested in studies



Research Methodology

- 14 papers, 56%
- Lack of understanding terms quality of life/quality of death and definition of target population for multimorbid groups
- Data available for researchers
- Incongruency between the end-of-life care organization's understanding of the research and the research itself



Research Methodology

- More longitudinal studies
- More studies on more topics within HPC and in residential hospices



Implications for Research

- Establishing a palliative care research network such as PCPCRC
- Improving criteria for research. Ex: operationalization of terms
- Creating broad eligibility criterion
- Consistently screening participants
- Clearer connections between research and clinical teams



Implications for Practice

- Standardizing training procedures across end-of-life care practitioners and incorporating end-of-life care training into all health care education
- More support for caregivers



Implications for Policy

- Creating policies or agreements between service providers and different cultural communities
- Making HPC services available for those in hard to access communities
- Guidelines addressing community funding, research funding, seat funding and proof of consent funding

Conclusions

- Literature pertaining to gaps in palliative care is limited
- Each of the themes can help direct future funders/researchers
- Further research required

Questions?

THANK YOU!

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