Experiences of Caring for Persons Living with Dementia at the End of their Lives

Dotsa Bitove Wellness Academy

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Purpose of Our Study

The purpose of this research is to contribute to the national conversation about end-of-life (EOL) care and contribute understanding about the barriers and opportunities for providing quality EOL care for persons living with dementia.

Our purpose fits with the Quality End-of-Life Coalition whose mission centres on the belief that “all Canadians have the right to quality end-of-life care that allows them to die with dignity, free of pain, surrounded by their loved ones, in a setting of their choice” (www.chpca.net/projects-and-advocacy/the-quality-end-of-life-care-coalition-of-canada.aspx)

Questions to Consider

- What resonates with you when you see the creative works and hear the experiences of healthcare professionals who provide end-of-life care for persons living with dementia?
- What, if anything, challenges you?
- How can you contribute to further this conversation?
- What can you share that is working in your setting and in your practice?
- How might the ideas presented today from the healthcare professionals experiences inspire you?

Objectives of Our Study

- To explore healthcare professional experiences of caring for persons living with dementia at the end of their journey;
- To explore the values, beliefs and assumptions that support and/or act as a barrier to providing quality care;
- To explore understandings about when palliative end-of-life care begins;
- To further infuse the arts into healthcare practices and scholarship

Palliative Care and End-of-Life

“Palliative care is an approach that improves the quality of life of [persons] and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.” World Health Organization

“End of life care involves treatment, care and support for people who are nearing the end of their life. It’s an important part of palliative care.” (https://www.mariecurie.org.uk)

https://pallium.ca/ - for definitions of palliative and end of life care and the difference in concepts

Literature Review

- Literature found exploring barriers to quality palliative care for persons living with dementia focused on: the educational needs of staff and families, the biomedical challenges that arise, such as, pain, treatment of pneumonia, and lastly the system barriers to quality care;
- No studies found that explored the values, beliefs and assumptions health professionals hold about caring for persons with dementia at the end of their lives, and how these ideas influence the care they provide;
- No research found that explored how health professionals experience caring for persons living with dementia at the end of life using the arts

Research Question

“What it is like to care for persons living with dementia who are receiving end-of-life care?”

Research Methodology

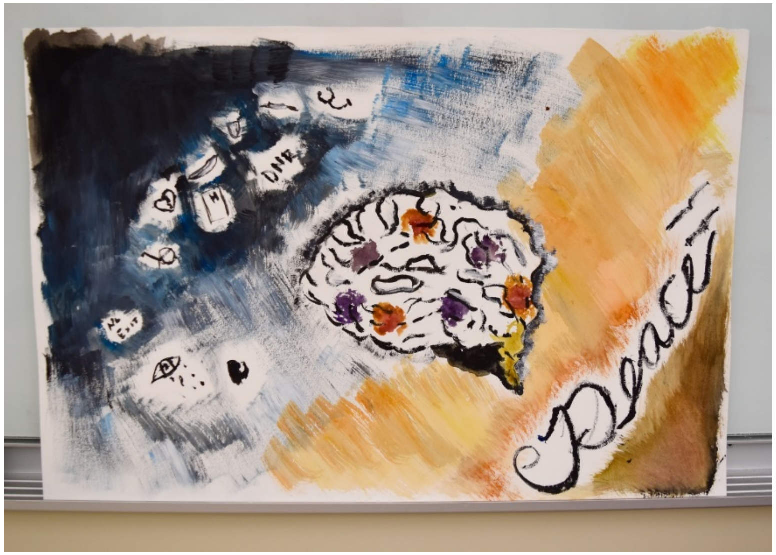
- A/r/tography is an arts-based method, a form of action research that involves working with communities of practice who share a commitment to search for meanings and new insights of a particular phenomenon (Irwin & Springgay, 2008).

Research Methods

Workshop #1: Focus group discussion; meditation, creation of an artistic expression; discussion of artistic expressions.

Workshop #2: Focus group discussion; meditation, creation of small acrylic painting; discussion of meaning of paintings.

Workshop #3: Discussion of findings, reflections and new discoveries.



Participant Description

- Total # of Participants: 7
- 5 Registered Nurses:
  - # of years worked: (1) 4 years, (2) 5 years, (3) 6 years, (4) 16 years, (5) 30 years
  - ICU, General Medicine, LTC, Geriatric Psychiatry
- 2 Therapists, 1 Recreational Therapist and 1 OT:

    # of years worked by participants: (1) 5.5 years, (2) 11 years
  - Geriatric psychiatry

Centre of Intention

Living with Pain

Pain

Strawberry Hill

Peace

Puzzle Symphony

Vantage Point

We Are Dementia

Themes from Session 1

Darkness and Light Coexist on the Journey

Blackness/ guilt

sadness/ tears/

conflict/ judging/ frustration/ anger/ pain/death/hurting/

creating suffering/ messy/ chaotic/ opposing voices/ dementia and challenges/ walking through the valley/ moral distress

Themes from Session 1

Darkness and Light Coexist on the Journey

Yellow/Gold

rewarding/peace/ wholeness/ sunrise/ not the end/ letting go/ love/ transformation/ resolve/ togetherness/ family love/ feelings of home/ relationships/ connection

Themes from Session 1

Dissonance emerges amid Complex Tensions of Discernment

Themes from Session 1

Support of the Care Collective with Consistent Communication

Eases Isolating Burden

Theme from Session 1

Patterns of Peace, Relief, Privilege and Sorrow coexist with Relationships

Final Words of Session 1

Togetherness

Wholeness

Transformation

Judgement

Resolve

Transition

Learning Experience

Artist Perspective on Session 1

"Two compositional themes are immediately striking around which the participants organized their ideas and marks: centredness and fragmentation.

Colour also seems to be particularly relevant… – playing on lightness and dark."

Additional Theme: Session 2

Creating comfort and loving connections brings a sense of fulfillment. Feelings of despair emerge when participating in tortuous end of life care.

Titles of Paintings Session 2

Into the Blue

Transformation

The person who lost his way.

Fading away

Stage Four

Sweet Lining

Loving lights

Artist Perspective on Session 2

"The movement and mood is softer, gentler…almost peaceful…. There is very little darkness in these pieces, with the dominant colours being blues, whites, pinks, yellow, gold. Deep red tones are used sparingly here. Where there is black, it appears in the bottom corner – almost inconsequential. Again, the movement and mood is less about fragmentation (as in the Session One work) and more about a dispersion of energy that is not grounded. The works have an almost floating or soaring quality."

Session Three

Time to present and reflect upon themes as a collective.

Relational Ethics

- Mutual Respect
- Engagement
- Embodied Space
- Environment
- Uncertainty

(Bergum & Dossetor, 2005)

End-of-Life Resources from the Alzheimer's Society

- The "Dementia and end of life care" section of our website
  - This resource contains sub-sections such as: "What decisions will I need to make?"; "What do I need to know about caring for the person?"; "How do I care for myself and my family?"; and "What practical information should I know?". This is a resource that is only available online, but the user has the option to download and print PDF versions of the materials.
- Ambiguous loss and grief: A resource for individuals and families (available in print and online)
  - This resource is meant primarily to assist caregivers in developing a better understanding of how loss and grief can affect them and the person with dementia. It also provides information to help people with dementia live with their own grief while living as well as possible with the disease.

End-of-Life Resources from the Alzheimer's Society

- Ambiguous loss and grief: A resource for healthcare providers (available in print and online)
  - This resource is to help healthcare providers, Alzheimer Society staff and volunteers to gain a better understand off how loss and grief affect people with dementia and their caregivers. It provides the reader with strategies to assist families with their grief and to support caregivers in maintaining a connection with the person with dementia while also building their own resilience through the disease progression.
- Dementia and staff grief: A resource for healthcare providers (available in print and online)
  - This resource is meant to help organizations gain a better understanding of the losses experienced by staff caring for people with dementia across the continuum of care. It also provides ideas and strategies for employers to support their staff through grief, and tips for self-care.
- The final document in our five-part series on the stages of Alzheimer's Disease - End of Life (available in print and online)

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Thank you for Engaging in our Research – Keep the conversation going!

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References

Bergum, V. & Dossetor, J. (2005). *Relational Ethics: The full meaning of respect.* Hagerstown Maryland: University Publishing Group.

Irwin, R.L., & Springgay, S. (2008). A/r/tography as practice-based research. In M. Cahnmann-Taylor & R. Siegesmund (Eds.). *Arts-based research in education. Foundations for practice* (pp. 103-124).). New York, NY: Routledge.