Looking Forward, Looking Back: What History Can Teach us About the Integration of a Palliative Approach to Care

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Outline

- Who has palliative care been most designed to serve?
- Who has palliative care been least designed to serve?
- Why the emphasis on a palliative approach to care? Why now?
- What do we mean when we say a palliative approach to care?
- What are the implications of integrating a palliative approach to care?
- What can we learn from the history of the development of palliative care as we begin to talk about a palliative approach to care and move forward into the future?
Who Has Palliative Care Been Most Designed to Serve?
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Who Has Palliative Care Been Most Designed to Serve?
Who has palliative care been least designed to serve?

- 79 year old Welsh male
- Grew up in a good home; said father was a bit “rough”
- Married with 2 children; Employed in the trades
- Marriage dissolved; becomes estranged from family; becomes unemployed; on income assistance
- Lives on a boat

George
Diagnosed with advanced prostate cancer; trt options minimal
Hospitalized for kidney failure, gets treatment and is to be discharged
While in hospital boat sinks
No home; discharged to a single room occupancy hotel
George

- Mistrusting of the health care system. Has a GP and specialist, but refuses home nursing care – feels “judged”
- Rent is ~ $900/month; Has ~$450 to live on each month after rent
- His dream is to build a boat and go back and live on the water
- A friend in his boating community helps him to secure his “new digs”
George

- Cannot afford moorage so boat is anchored about a 30 minute row to and from the shore
- Over time he gets progressively sick, weak, fatigued and experiences unrelenting pain – he is dying
- His boating friend provides palliative care for the final weeks, on the boat
Eventually got taken off his “boat” by the Canadian Coast Guard
Admitted to Hospice for the last few days of life
Main support person = research project coordinator
Why could we not keep George on his boat?

- What prevented us from making this happen?
- What would present day palliative care have to offer George to help him achieve what was most important to him?
Model of palliative cancer care
‘Organ system failure’ trajectory

Begin to use hospital often, self-care becomes difficult

Time: ~ 2–5 years, but death usually seems ‘sudden’

Terminal phase

“Well, number one you have to realize that this is a progressive disease and there is no cure for this. Well guess what, now I have a chance to keep on keepin’ on.”

- Stanton Kolansky, COPD

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Dying on the streets: UVic study examines palliative care for the homeless

"We were hearing all kinds of stories, and service providers themselves were feeling very distressed"

By Roshini Nair, CBC News  Posted: Aug 15, 2016 1:04 PM PT  Last Updated: Aug 15, 2016 1:04 PM PT

It's an uncomfortable truth, but some people spend their last days in parks, streets and their cars, alone and in pain.

University of Victoria researcher Kelli Stajduhar has been leading a study looking at palliative care options for the homeless after hearing stories from outreach workers about people dying in the streets.

"We would really like to think as a society that we care for our people, especially at the end of their lives," she said.
Why Not Palliative Care for All?
Why Not Palliative Care for All?
The “not enough” thesis

Not enough resources
Not enough hospice beds
Not enough home-based palliative care
Conceptualizations of Hospice/Palliative Care

- Conceptualizations of hospice palliative care as a place – an inpatient unit where people go to die and where they are cared for by providers who specialize in care of the dying
- Little consideration of hospice palliative care as a philosophy and approach to care
- Little recognition that people die in all locations in the health care system and that everyone has a responsibility for providing EOL care
- These conceptualizations resulted in a general belief, particularly in acute care, that these patients “don’t belong”

Emphasis on integrating a palliative approach across sectors of healthcare for all people who have life-limiting chronic illnesses

* Residential care
* Hospital-based care
* Community-based primary care
iPANEL: What Do We Do?

- Practical relevance toward improving palliative and end-of-life care in British Columbia
- Inform health service decision-making and policy development
- Will result in sustainable changes to the delivery of health care

As researchers, clinicians, and administrators, we work collaboratively to synthesize evidence and conduct research on integrating a palliative approach into the care of those facing advancing chronic life-limiting illness.

www.iPANEL.ca
Palliative approach

- Kristjanson et al. (2003) articulated a “palliative approach” as care for those with advancing chronic illnesses who may not require specialized palliative care services and who would benefit from having their end of life care concerns identified much earlier in the illness trajectory.

- The World Health Organization similarly emphasizes a palliative approach to care that is applicable early on in illness trajectories.

- The Worldwide Palliative Care Alliance (2014) emphasized that palliative care be adopted by all, not just by professionals specializing in palliative care.
Why is Research on a Palliative Approach Important?

- Population aging means more people are living with advancing, chronic and life-limiting illness, often with multiple interacting medical and social problems.
- 80% of all deaths are caused by end stage chronic diseases such as heart, lung and kidney disease, cancer, dementias and general frailty.
- However, only 16% to 30% of people who die are identified as dying and receive palliative care services.
- The majority of people who access palliative care services have cancer; most people with advancing chronic life-limiting illness DO NOT access palliative care services.
Delineate key characteristics of a palliative approach found in empiric literature

Contribute to conceptual clarity on a palliative approach to care
Knowledge Synthesis

identifying a **palliative approach** in the literature...

**Concepts that reflect palliative care**
- hospice
- palliative
- end-of-life
- supportive care
- advance care planning
- patient/person centred care

**principles of palliative care**

**chronic life-limiting illness**
- chronic disease / illness
  - diabetes
  - kidney disease
  - emphysema, COPD
  - congestive heart failure
  - many neurological disorders, including Alzheimer’s disease
Methods

Literature search and article selection

Search of 10 databases → 190,204 search results

Computer-assisted approach helped narrow results to 91 research articles

Narrative synthesis and thematic analysis identified essential characteristics of a PA
Knowledge synthesis

3 Essential Characteristics:

**Adopt**

**Adapt**

**Embed**

What Is a Palliative Approach?

A palliative approach involves

• adopting the foundational principles of palliative care
• adapting the palliative care knowledge and expertise to the illness trajectories of people with chronic life-limiting conditions
• embedding this adapted knowledge and expertise “upstream” into the delivery of care across different healthcare sectors and professions
ADOPT an UPSTREAM ORIENTATION towards the needs of people who have life-limiting illnesses and their families.

Two conditions required of care providers to achieve an upstream orientation:

1. understanding different chronic life-limiting illness trajectories and
2. identifying where people are on those trajectories.
ADAPTATION OF PALLIATIVE CARE KNOWLEDGE AND EXPERTISE

Two questions guide this adaptation:

1. Which principles and practices from palliative care should be applied to people with chronic life-limiting illnesses more generally?

2. How do these principles and practices need to be adapted to ensure their fit with the needs of disease-specific patient populations?
Need for greater capacity within the healthcare system to fully address the evolving end of life care needs of people who chronic life-limiting illnesses

Partnerships with a range of healthcare providers—generalists, PC specialists, chronic disease specialists, community partners, people with lived experience
Not early palliative care
Not really shared care
A palliative approach is different than specialized palliative care. It takes the principles of palliative care and ADOPTS, ADAPTS, EMBEDS.
A palliative approach takes principles of palliative care and ADOPTS them EARLY in the course of person’s life-limiting condition.

**HOW?**

- **A**sk yourself: “Does this person have a life-limiting condition?” “Would this person benefit from a palliative approach?”
- **D**evelop an understanding of the illness course and where the person is along their journey.
- **O**pen conversations with people and their families to gauge understanding of their illness, what is most important to them, and their preference for care.
- **P**rioritize care - focus on what is important to people and their families.
- **T**ell people and their families about the illness and what can be expected in the future to inform their goals of care.
A palliative approach takes principles of palliative care and ADAPTS strategies to meet patient and family needs.

**HOW?**

- **A**cknowledge the anticipated course of the illness in the plan of care, not just in the treatment
- **D**etermine and treat symptom distress alongside disease treatment
- **A**djust the care plan to reflect the person’s goals of care
- **P**repare the person and family for anticipated changes and the possibility of dying
- **T**ailor palliative knowledge and skill to the chronic condition
A palliative approach takes principles of palliative care and EMBEDS practices into usual care in settings that do not specialize in palliative care.

**HOW CAN LEADERS EMBED A PALLIATIVE APPROACH?**

- **Enable** support for early integration in and across settings.
- **Mandate** processes for patient and family perspectives to be sought and communicated.
- **Build** confidence and competence by interactional education, mentorship and peer support.
- **Ensure** access to resources, mentors and specialist palliative care teams.
- **Dedicate** time for providers to be involved in creating practical tools and processes for their setting.

**Where?**
In all settings, across the continuum of care.

**When?**
Early in the course of a chronic life-limiting condition.

**Who?**
Everyone working with people with life-limiting conditions.
Shift your care to a palliative approach

https://www.youtube.com/watch?v=sABo3gZoAcM
What are the implications of integrating a palliative approach to care?
(Re)theorizing Integrated Knowledge Translation: A Heuristic for Knowledge-As-Action

Gweneth Harrick Doane, PhD; Sheryl Reimer-Kirkham, PhD; Rosemary Mooney, RN, PhD, MSN; Kelli Stajduhar, PhD; Richard Sawatzky, PhD; Barry King, RN, PhD; Cheri Ethier, RN, PhD; and Cheryl Northcote, RN, PhD

Abstract

This study used a qualitative approach to explore the feasibility of a new approach to knowledge translation. The study used a mixed-methods design, with focus group interviews, focus group discussions, and individual interviews. The findings indicate that the approach is feasible and can be used to support the integration of knowledge into practice.

Translational Scholarship and a Palliative Approach

Enlisting the Knowledge-As-Action Framework

Sheryl Reimer-Kirkham, PhD; Gweneth Harrick Doane, PhD; Elisabeth Antje Feust, MSN; Barbara Pesut, PhD; Pat Porterfield, MSN; Della Roberts, RN, PhD; Nicole Wikjord, RN, PhD

Based on a retooled epistemology for knowledge translation (KT) that problematizes the “know-do gap” and conceptualizes the knower, knowledge, and action as inseparable, this paper describes the application of the Knowledge-As-Action Framework. When applied as a heuristic device to support an inquiry process, the framework with the metaphor of a kite facilitates a responsiveness to the complexities that characterize KT. Examples from a KT demonstration project on the integration of a palliative approach at 3 clinical sites illustrate the interconnectedness of 6 dimensions—the local context, processes, people, knowledge, fluctuating needs of patients, and goals of palliative care, evaluation, inquiry, knowledge translation, models, palliative care, translational scholarship.

Cancer, Palliative Care, and the Problematical Nature of Dying

Kelli L. Stajduhar

Nurses encounter people with life-limiting illness in virtually every sector of the health-care system. In the care of the dying, the role of nurses is central, as the goal typically moves from one of care to one of care (Coluzzi & Rhiner, 1996). Nurses spend more time with people who are dying than anyone else in the health professions (Brug, 1993; Falkhoury, 1998; Murray Frommelt, 1991) and are, therefore, perfectly positioned to influence the care that dying people and their family members receive. Allive care nurses pride themselves on adopting a “whole person” approach to care, one that promotes quality of life along the illness trajectory, across the lifespan, and with a focus on both the dying person and those who are significant to him or her (Beckstrand & Archoff, 2005; Coyle, 2006). Key concepts associated with palliative care have been defined. They include dignity, hope, comfort, quality of life, knowing the patient, teamwork, suffering, and caring for patients (Stajduhar, 2004). Palliative care nursing has emerged as a specialty along other nursing specialties such as critical care nursing, gerontological nursing (Canadian Nurses Association, 2011).

Discourse

Chronic Illness, Palliative Care, and the Problematical Nature of Dying

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Death Is a Social Justice Issue

Perspectives on Equity-Informed Palliative Care

Sheryl Reimer-Kirkham, PhD, RN; Kelli Stajduhar, PhD, RN; Bernie Pauly, F; and Ryan McNeil, Ph.D

All too often, palliative vulnerable, being deficits in the social justice analysis need to be addressed. This article focuses on palliative care and the need to address the social justice issues that affect patients and families.

Abstract

Advances in technology and drug therapy have revolutionized the care of cancer patients. This has led to improvements in symptom management, quality of life, and survival. However, the underlying ethical implications of these advances have not been fully explored. This paper explores the ethical implications of these advances, including the potential for exploitation and the moral obligations of health care professionals. The paper argues that, in order to address the ethical implications of these advances, health care professionals must adopt a transformative approach that focuses on the social justice issues that affect patients and families. The paper concludes that this approach must be implemented in order to ensure that patients and families receive the care they need and deserve.
Integrating a Palliative Approach to Care

- Promotes the patient, family, unit staff and physicians to “get on the same page” about a plan of care, prioritize the patient’s goals and preferences, and work toward facilitating quality of care and a quality dying experience.

- Fosters confidence in the team to have sensitive conversations that enable care planning that matches patient goals and preferences.

- Builds cohesive teams that feel integrity in their work

- Creates awareness about the importance of identifying and recognizing patients who are on a palliative trajectory
Lessons Learned

- Integration of a palliative approach requires executive leadership to make it an organizational priority.
- Ongoing education and mentorship from clinical leaders is needed to coach, encourage and do necessary implementation work.
- Education and tools alone will not create culture shifts. Engagement, and ongoing mentorship and coaching of unit staff is needed.
- Adaptation of and embedding practice support tools into current work flow is required to support clinical decision making.
- Engaged partnerships between the clinical teams and researchers facilitates rigorous evaluation and provides data to inform ongoing planning and action.
Final Reflections

Roots of hospice tied to early religious traditions

Institutionalized Death

Medicalization of Death
Modern Hospice Palliative Care Movement
THE ROUTINIZATION OF HOSPICE: CHARISMA AND BUREAUCRATIZATION

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Abstract—In 25 years the number of hospices in Britain has multiplied from under 15 in 1965 to over 430 in 1991. During this period, often working out with the mainstream health system, the hospices actively sought to transform terminal care. More recently a process of diversification and legitimation has meant that hospices have become increasingly subject to mainstream influence. Using Weber's concept of charisma we examine the development of the hospice movement during this period of expansion. We suggest there are a number of factors leading to the routinization of hospice care including the ways in which it was sponsored and developed at the local level, and pressures toward bureaucratization and professionalization. We make links with recent developments in the health services. Finally we consider whether it is possible for the hospice movement to sustain its founding ideals.

Key words—hospices, charisma, terminal care, social movements, health organization
Final Reflections

- Hospice and palliative care mostly originated outside the health care establishment.
- The movement has now (for the most part) become part of the mainstream of health care provision, an exemplar of good practice in terminal care, and an influential player in policy making.
- Entry into the ‘mainstream’ has been significant, but not without problems and perhaps some unanticipated consequences.
Final Reflections

- Over reliance on ‘specialty models’ – “specialized palliative care is not the main way we should deal with dying but it’s an important part”
- Creep of the biomedical model – emphasis on the “physical and symptoms” at the expense of other important concerns
- Professionalization
- Community ownership and conceptualizations of death and dying – once considered a civic and social responsibility has given way to all the trappings of institutionalized, professionalized, medicalized and “other-ized” systems of care
To What Extent Do these Issues Compromise the Early Ideals of the Modern Hospice Palliative Care Movement?
Final Reflections

- Somewhat
- BUT …. We do not want to lose what we have gained
- Learn from our history
- Move forward in thoughtful ways
- Reincorporate some that might have been lost along the way – an emphasis on the social aspects of dying, compassionate communities, engaging our communities in what is important
Community workers, street family hit hard by B.C.’s opioid crisis

DR. KELLI STAJDUHAR AND ASHLEY MOLLISON
CONTRIBUTED TO THE GLOBE AND MAIL
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In the years when hundreds of British Columbia's young men died from opioid withdrawal, the people they loved were left behind with memories they've carried with them for more than a decade. They are the street family members who lived and died alongside the opioid crisis. They are the community workers who struggled to care for them.

The street family members who lived through the winter of 2016-17, when hundreds of people died from opioid withdrawal, were left with memories they'll carry with them. They are the community workers who struggled to care for them.
SHELLY