

How do we Destigmatize Palliative Care?

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University Health Network

Objectives

- Review how palliative care has changed
- Explore how and why palliative care is stigmatized
- Discuss possible solutions

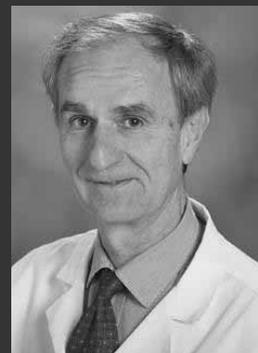
Origins of palliative care: 1960's-80's

- Catholic movement
- Driven largely by beliefs and ideals, rather than by evidence
- Stimulus was founding by Cicely Saunders of St. Christopher's Hospice in London
- Mainly in cancer populations



Palliative care: 1990's-present

- Increasing academic focus, specialization
- "Medicalization" of hospice
- Growing evidence base
- Extended focus on "life-threatening illness" rather than on end of life
- [Growth of euthanasia movement, and "assisted dying"]



Definitions of Palliative Care

"Palliative care is active compassionate care of the terminally ill at a time when they're no longer responsive to traditional treatment aimed at cure and prolongation of life and when the control of symptoms, physical and emotional is paramount. It is multidisciplinary in its approach and encompasses the patient, the family and the community in its scope."

Palliative Care Foundation, Toronto, 1981

"Palliative care is the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms and of psychological, social and spiritual problems is paramount"

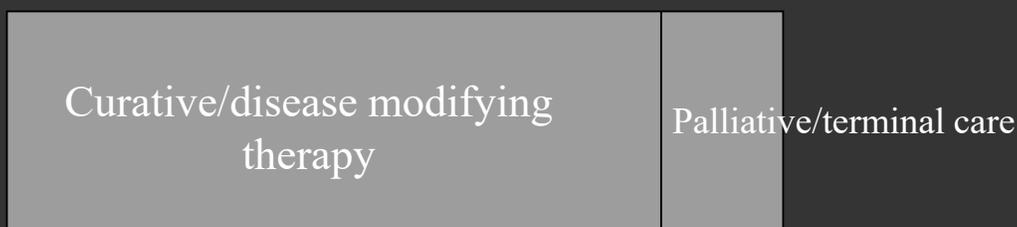
World Health Organization, 1990

Palliative care is an approach that improves the quality of life of patients 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.

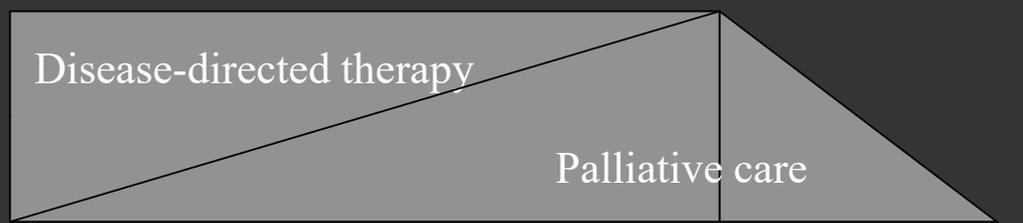
World Health Organization, 2002

Canadian Hospice Palliative Care Association, 2002

Traditional view



"New" model



↑ Diagnosis

↑ Patient's death

Bereavement



Association Between Palliative Care and Patient and Caregiver Outcomes

A Systematic Review and Meta-analysis

Dio Kavalieratos, PhD; Jennifer Corbelli, MD, MS; Di Zhang, BS; J. Nicholas Dionne-Odom, PhD, RN; Natalie C. Ernecoff, MPH; Janel Hanmer, MD, PhD; Zachariah P. Hoydich, BS; Dara Z. Ikejiani; Michele Klein-Fedyshin, MSLS, BSN, RN, BA; Camilla Zimmermann, MD, PhD; Sally C. Morton, PhD; Robert M. Arnold, MD; Lucas Heller, MD; Yael Schenker, MD, MAS

- 43 RCTs, 19 including only patients with cancer
- Meta-analysis:
 - Statistically and clinically significant improvement in patient QOL and symptom burden at 1-3 mo
- Narrative synthesis
 - Palliative care consistently associated with improvements in advance care planning, patient and caregiver satisfaction, and lower health care utilization

ASCO Clinical Guideline

Combined standard oncology care and palliative care should be considered early in the course of illness for any patient with metastatic cancer and/or high symptom burden.

ASCO Provisional Opinion
Smith et al. J Clin Oncol 2012

Inpatients and outpatients with advanced cancer should receive dedicated palliative care services, early in the disease course, concurrent with active treatment.

ASCO Clinical Guideline
Ferrell et al. J Clin Oncol 2016

Social ecological model of health



CMAJ

Research

Perceptions of palliative care among patients with advanced cancer and their caregivers

Camilla Zimmermann MD PhD, Nadia Swami BSc, Monika Krzyzanowska MD MPH, Natasha Leighl MD MMSc, Anne Rydall MSc, Gary Rodin MD, Ian Tannock MD PhD, Breffni Hannon MB ChB

CMAJ Podcasts: author interview at <https://soundcloud.com/cmajpodcasts/151171-res>

See also www.cmaj.ca/lookup/doi/10.1503/cmaj.160206

71 patients and caregivers

- semi-structured interviews after the trial
- asked about perceptions of pc

Initial perceptions

Sources of these perceptions

Change in perceptions

Initial perceptions of palliative care

<i>Theme</i>	Control Group	Intervention Group
Death, end of life	What comes to mind is bedridden, death bed, finality. (P062c)	It means death to me. It does. The end. (C068i)
Comfort care	I thought what the heck is that? Then I realized they're just trying to keep you comfortable until you die. (P056c)	Just they take you off medication and put you on just comfort care. (P008i)
No more choices, nothing left to do	The stage of palliative care, hope is kind of more or less gone. (C070c)	Dying, end of life, nothing left to do. (P025i)
Loss of autonomy	It just sounds old and sick and helpless. (P065c)	When you think palliative care, you think bedridden, unable to look after yourself on any level. (P040i)
A place to die	Well, to me, palliative care is the place where you go to die. (C064c)	And it's a place to die. But they make you as comfortable as possible...(P023i)
Unsure of meaning	Scares me a bit.(...) Even though I don't really know what it is. I don't know really what it is. (C059c)	It's like a foreign language, palliative care, yeah, but I didn't really have any connection to what it was. I just had an idea that it was when people were dying they had palliative care. (P034i)

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Sources of perceptions

The very first time that one of these home nurses came to my house, right, she said... "You're not in palliative care, like you're dying of anything, are you?" And I just looked at her, I remember just saying, "Oh, is that what that means?", I said. (P002i)

My ex-husband actually died. [...] He died in three months. But for the first period, they were treating him and then they said, "We can't do anything else, he's in palliative care." (P031i)



Perceptions after receiving EPC

Theme

Intervention Group

More comfortable attitude towards palliative care

I think the more contact that we have with people like [palliative care team], it's just, it's more normal (...) Our "normal" now includes coming to the hospital; he goes and gets his CT scans, he goes to oncology, he also goes and sees [palliative care physician] and palliative care. That's the norm. It's just a part of what happens when you go to [the hospital]. (C046i)

Team useful but name problematic

It's just one of those...it's like anybody who has been raised with certain values or beliefs. Palliative care, in my mind, has always been final stages. Now I know intellectually, rationally, palliative care is not final stages but emotionally I still carry that term as, perhaps a slightly fearful term. (P024i)

The care I received is not palliative care

Somehow it still doesn't really change my feeling about palliative care because I think she [palliative care physician] gave me wonderful care. Somehow I can't equate what I experienced with her as palliative. (P040i)

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“The P-word”

I don't use that palliative word — the P word. (P066i)

Well I think just in my own had, just to make me feel comfortable, I referred to her as my “medication specialist” ... I say that I'm seeing my “medication specialist.” Why? Because if I told people I was seeing a palliative care doctor, they would think I was going to die in a few weeks or months. (P040i)

I don't tell people I'm seeing somebody in palliative care. I just, I say, “Oh one of the doctors at [hospital] told me this or that” ... “Oh, one of your team doctors?” “Yeah, yeah, one of the team doctors.” I don't ... I don't talk about it. ... They may just get so scared they walk away and so it's best not to say anything. (P022i)

Solutions: renaming or reframing

Palliative care = EOL care and that's OK

Because I think I can be realistic and that is the end. We are all going to die. I think it's more difficult for others to accept that. (C068i)

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Name needs to be changed (to change perception that PC = EOL care)

I think it's, it's imprinted in my mind that palliative care is people dying. And I think it would be hard to shake that (...) Yeah, I think you have to change the name (...) for people to change their perception. (P031i)

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Rebranding

I don't know how you do it, but if somehow the medical profession could explain to the public better what palliative care is, it takes some of the fear and the stigma away from it, the negative stigma away from it, that it isn't necessarily the last three weeks of your life kind of thing, when you're doped up and don't know anyone's around. (P013i)

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JOURNAL OF CLINICAL ONCOLOGY

ORIGINAL REPORT

Referral Practices of Oncologists to Specialized Palliative Care

Kirsten Wentlandt, Monika K. Krzyzanowska, Nadia Swami, Gary M. Rodin, Lisa W. Le, and Camilla Zimmermann

Listen to the podcast by Dr Bruera at www.jco.org/podcasts

Surveyed Canadian Medical, Radiation and Surgical Oncologists

- response rate >70% (603/839)
- 85% referred “usually” or “always”, but 1/3 referred only after stopping all treatment

Factors influencing early referral (at diagnosis or during chemo):

- Satisfaction with availability of PC service
- Acceptance by PC service of patients on chemotherapy
- Completing a rotation in palliative care
- 1/3 agreed they would refer earlier if palliative care was renamed supportive care

What do palliative care physicians think?

Surveyed Canadian Primary and Specialized PC physicians

- response rate 71% (531/746): 52% PPC, 48% SPC
- provided pc mainly for cancer patients (84% SPC, 65% PPC)
- >90% stated referral should occur at diagnosis or prognosis >6mo
 - Only 20% received referrals at >6mo

Sorensen et al, ASCO 2016

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>1/3 of PPC and 1/5 of SPC agreed/strongly agreed "the specialty of palliative care should be renamed supportive care"

- 1/2 of PPC and 1/3 of SPC thought renaming would increase patient comfort with early referrals

Sorensen et al, ASCO 2016

Mixed Messages about Palliative Care

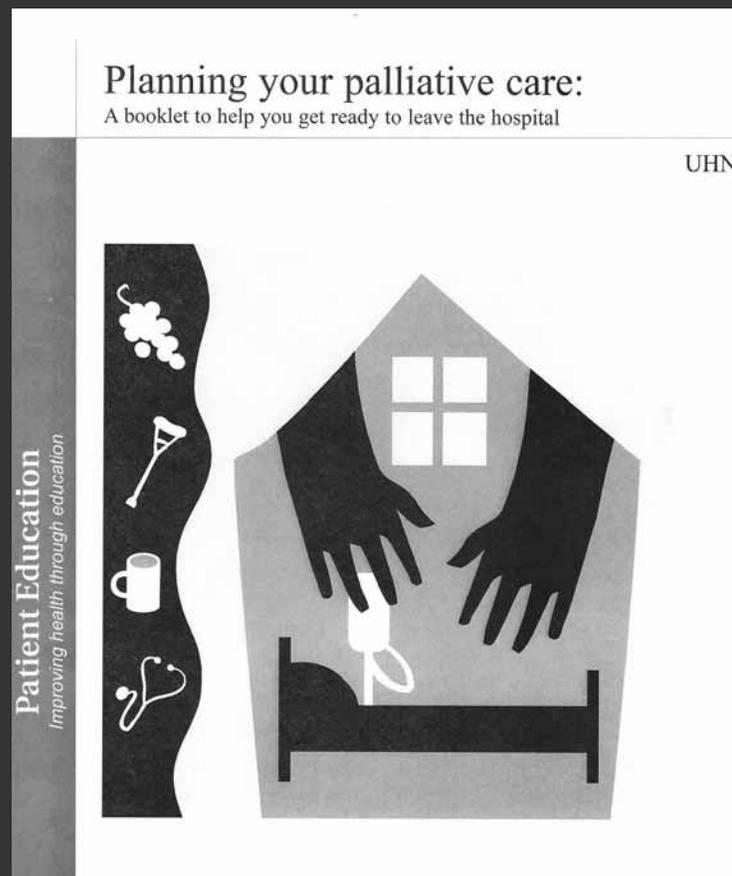


Canadian Virtual Hospice

What is palliative care?

Palliative care is a type of health care for patients and families facing life-threatening illness. Palliative care helps patients to achieve the best possible quality of life right up until the end of life. Palliative care is also called end-of-life, or comfort care.

http://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home.aspx





Destigmatizing palliative care

Policy:

- Policies/definitions that support early pc

Community:

- "Rebrand" palliative care
- Media/social media

Organizational:

- Educate patients and clinicians about pc
- Enable early pc (clinics, care plans, etc)
- Expand services beyond cancer
- Interprofessional collaboration/research

Interpersonal:

- Explain and re-explain
- Avoid "palliative" as a label
- Keep messaging consistent!

Individual

Thank-you

PM palliative care research and clinical team

Medical oncologists at PM

Patients and families participating in research

Rose Chair in Supportive Care,
Faculty of Medicine, University
of Toronto

PM Foundation

Ontario Ministry of Health and
Long Term Care

