Evidence for early palliative care: Are we there yet?

Camilla Zimmermann, MD PhD

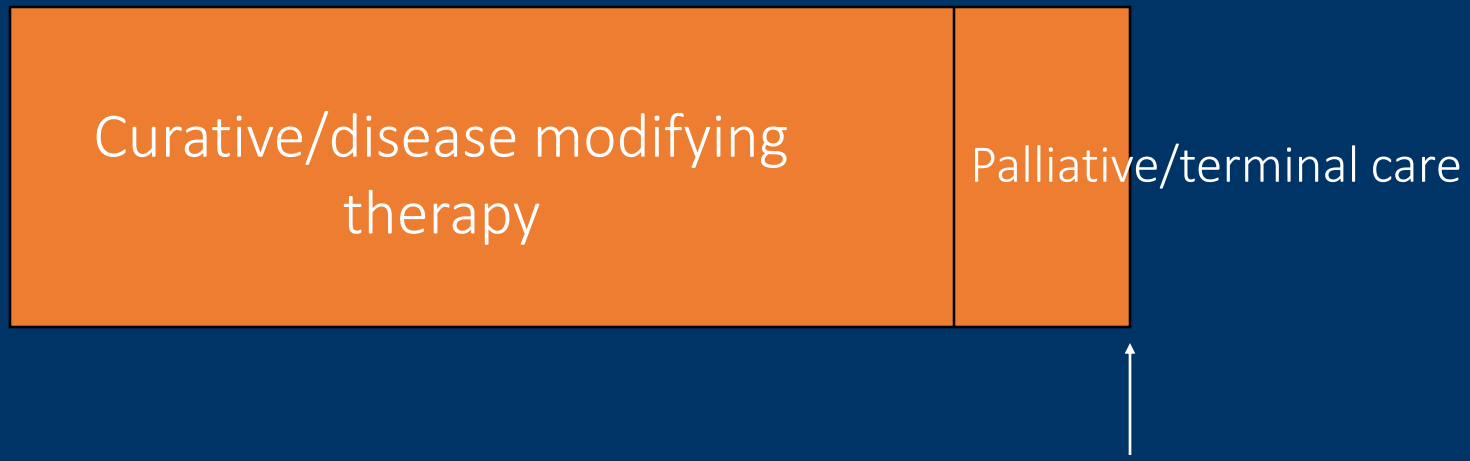
Professor of Medicine and Rose Family Chair in Supportive Care,
Department of Medicine, University of Toronto
Head, Division of Palliative Care, Princess Margaret Cancer Centre/
University Health Network

Objectives

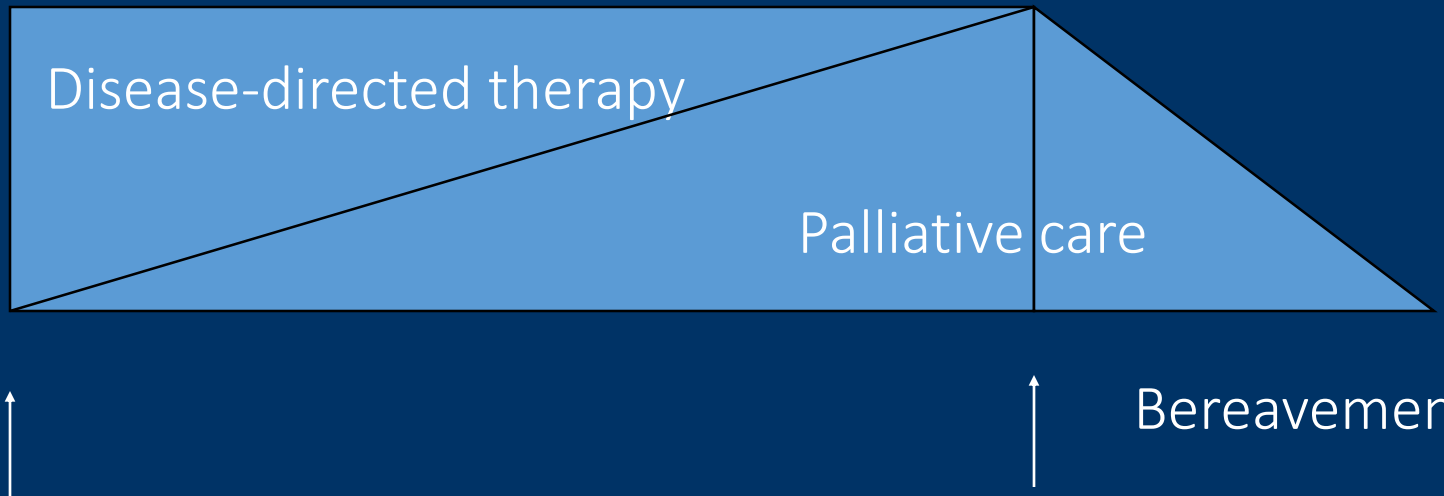
- Describe the results of trials demonstrating benefits of early palliative care in advanced cancer
- Discuss barriers that prevent early palliative care and ways to overcome them
- Discuss possible new research directions

Canadian Hospice Palliative Care Association, 2002

Traditional view



"New" model



Contemporary definition of palliative care

- “an approach that improves the quality of life of patients and their families…

  …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.”

WHO, 2002

Where is the evidence?



Effectiveness of Specialized Palliative Care: A Systematic Review

Camilla Zimmermann; Rachel Riechelmann; Monika Krzyzanowska; et al.

JAMA. 2008;299(14):1698-1709 (doi:10.1001/jama.299.14.1698)

http://jama.ama-assn.org/cgi/content/full/299/14/1698

- 22 RCTs, 19 including patients with cancer
- Strong evidence for family satisfaction with care
- 4/13 studies assessing QOL had significant results
- Many were underpowered
- Challenges with recruitment, attrition, and co-intervention
- None specifically assessed early palliative care in patients with cancer

VOLUME 27 · NUMBER 2 · JANUARY 10 2009

JOURNAL OF CLINICAL ONCOLOGY

ORIGINAL REPORT

Phase II Study of an Outpatient Palliative Care Intervention in Patients With Metastatic Cancer

Matthew Follwell, Debika Burman, Lisa W. Le, Kristina Wakimoto, Dori Seccareccia, John Bryson, Gary Rodin, and Camilla Zimmermann

- Pilot trial of outpatient palliative care (PC MD, nurse)
- 150 pts, advanced cancer, prognosis > one month
- outcomes ESAS, FAMCARE at one week, one month

Table 3. ESAS Scores at Baseline, 1 Week, and 1 Month

	Baseline (n = 150)		Difference at 1 Week (n = 123)			Difference at 1 Month (n = 88)		
Variable	Mean	SD	Mean	95% CI	*P*	Mean	95% CI	*P*
EDS	39.5	17.8	−8.8	−11.2 to −6.3	< .0001	−7.0	−10.2 to −3.7	< .0001
TDS	47.8	21.5	−10.8	−13.7 to −7.8	< .0001	−8.9	−12.7 to −5.1	< .0001
Pain	4.6	3.2	−1.2	−1.7 to −0.6	< .0001	−0.9	−1.6 to −0.2	.01
Fatigue	6.5	2.7	−1.0	−1.4 to −0.5	< .0001	−0.7	−1.3 to −0.1	.02
Nausea	2.8	3.1	−1.2	−1.7 to −0.7	< .0001	−0.8	−1.4 to −0.1	.02
Depression	3.5	3.1	−0.7	−1.2 to −0.3	.002	−0.9	−1.5 to −0.3	.005
Anxiety	4.0	3.2	−1.6	−2.2 to −0.9	< .0001	−1.2	−2.0 to −0.5	.001
Drowsiness	4.5	3.2	−0.9	−1.5 to −0.4	.002	−0.9	−1.6 to −0.1	.02
Appetite	5.0	3.1	−0.9	−1.3 to −0.4	.0005	−0.6	−1.3 to −0.1	.05
Dyspnea	3.3	3.3	−1.0	−1.5 to −0.5	.0001	−0.8	−1.3 to −0.2	.009
Well-being	5.3	2.7	−0.2	−0.7 to 0.4	.53	−0.2	−0.8 to 0.5	.55
Insomnia	4.4	3.3	−1.1	−1.5 to −0.6	< .0001	−1.1	−1.8 to −0.4	.002
Constipation	3.9	3.6	−0.9	−1.5 to −0.3	.005	−0.9	−1.7 to −0.1	.03

Abbreviations: ESAS, Edmonton Symptom Assessment System; SD, standard deviation; EDS, Edmonton Symptom Assessment System Distress Score; TDS, Total Distress Score.

VOLUME 27 · NUMBER 2 · JANUARY 10 2009

JOURNAL OF CLINICAL ONCOLOGY

ORIGINAL REPORT

Phase II Study of an Outpatient Palliative Care Intervention in Patients With Metastatic Cancer

Matthew Follwell, Debika Burman, Lisa W. Le, Kristina Wakimoto, Dori Seccareccia, John Bryson, Gary Rodin, and Camilla Zimmermann

Table 3. ESAS Scores at Baseline, 1 Week, and 1 Month

	Baseline (n = 150)		Difference at 1 Week (n = 123)			Difference at 1 Month (n = 88)		
Variable	Mean	SD	Mean	95% CI	*P*	Mean	95% CI	*P*
EDS	39.5	17.8	−8.8	−11.2 to −6.3	< .0001	−7.0	−10.2 to −3.7	< .0001
TDS	47.8	21.5	−10.8	−13.7 to −7.8	< .0001	−8.9	−12.7 to −5.1	< .0001
Pain	4.6	3.2	−1.2	−1.7 to −0.6	< .0001	−0.9	−1.6 to −0.2	.01
Fatigue	6.5	2.7	−1.0	−1.4 to −0.5	< .0001	−0.7	−1.3 to −0.1	.02
Nausea	2.8	3.1	−1.2	−1.7 to −0.7	< .0001	−0.8	−1.4 to −0.1	.02
Depression	3.5	3.1	−0.7	−1.2 to −0.3	.002	−0.9	−1.5 to −0.3	.005
Anxiety	4.0	3.2	−1.6	−2.2 to −0.9	< .0001	−1.2	−2.0 to −0.5	.001
Drowsiness	4.5	3.2	−0.9	−1.5 to −0.4	.002	−0.9	−1.6 to −0.1	.02
Appetite	5.0	3.1	−0.9	−1.3 to −0.4	.0005	−0.6	−1.3 to −0.1	.05
Dyspnea	3.3	3.3	−1.0	−1.5 to −0.5	.0001	−0.8	−1.3 to −0.2	.009
Well-being	5.3	2.7	−0.2	−0.7 to 0.4	.53	−0.2	−0.8 to 0.5	.55
Insomnia	4.4	3.3	−1.1	−1.5 to −0.6	< .0001	−1.1	−1.8 to −0.4	.002
Constipation	3.9	3.6	−0.9	−1.5 to −0.3	.005	−0.9	−1.7 to −0.1	.03

Abbreviations: ESAS, Edmonton Symptom Assessment System; SD, standard deviation; EDS, Edmonton Symptom Assessment System Distress Score; TDS, Total Distress Score.

Effects of a Palliative Care Intervention on Clinical Outcomes in Patients With Advanced Cancer

The Project ENABLE II Randomized Controlled Trial

Marie Bakitas, DNSc, APRN
Kathleen Doyle Lyons, ScD, OTR
Mark T. Hegel, PhD
Stefan Balan, MD
Frances C. Brokaw, MD, MS
Janette Seville, PhD
Jay G. Hull, PhD
Zhongze Li, MS
Tor D. Tosteson, ScD
Ira R. Byock, MD
Tim A. Ahles, PhD

Context There are few randomized controlled trials on the effectiveness of palliative care interventions to improve the care of patients with advanced cancer.

Objective To determine the effect of a nursing-led intervention on quality of life, symptom intensity, mood, and resource use in patients with advanced cancer.

Design, Setting, and Participants Randomized controlled trial conducted from November 2003 through May 2008 of 322 patients with advanced cancer in a rural, National Cancer Institute–designated comprehensive cancer center in New Hampshire and affiliated outreach clinics and a VA medical center in Vermont.

Interventions A multicomponent, psychoeducational intervention (Project ENABLE [Educate, Nurture, Advise, Before Life Ends]) conducted by advanced practice nurses consisting of 4 weekly educational sessions and monthly follow-up sessions until death or study completion (n=161) vs usual care (n=161).

Main Outcome Measures Quality of life was measured by the Functional Assessment of Chronic Illness Therapy for Palliative Care (score range, 0-184). Symptom intensity was measured by the Edmonton Symptom Assessment Scale (score range, 0-900). Mood was measured by the Center for Epidemiological Studies Depression Scale (range, 0-60). These measures were assessed at baseline, 1 month, and every 3 months until death or study completion. Intensity of service was measured as the number of days in the hospital and in the intensive care unit (ICU) and the number of emergency department visits recorded in the electronic medical record.

Results A total of 322 participants with cancer of the gastrointestinal tract (41%; 67 in the usual care group vs 66 in the intervention group), lung (36%; 58 vs 59), genitourinary tract (12%; 20 vs 19), and breast (10%; 16 vs 17) were randomized. The estimated treatment effects (intervention minus usual care) for all participants were a mean (SE) of 4.6 (2) for quality of life (P=.02), −27.8 (15) for symptom intensity (P=.06), and −1.8 (0.81) for depressed mood (P=.02). The estimated treatment effects in participants who died during the study were a mean (SE) of 8.6 (3.6) for quality of life (P=.02), −24.2 (20.5) for symptom intensity (P=.24), and −2.7 (1.2) for depressed mood (P=.03). Intensity of service did not differ between the 2 groups.

Conclusion Compared with participants receiving usual oncology care, those receiving a nurse-led, palliative care–focused intervention addressing physical, psychosocial, and care coordination provided concurrently with oncology care had higher scores for quality of life and mood, but did not have improvements in symptom intensity scores or reduced days in the hospital or ICU or emergency department visits.

FIFTY PERCENT OF PERSONS WITH cancer are not cured of their disease[1]; however, with improved treatment even patients with advanced disease may live for years. Providing palliative care concurrent with oncology treatment has been proposed to improve quality of life for patients with advanced cancer.[2-8] The National Consensus Project Clinical Practice Guidelines for Quality Palliative Care recommends palliative care referral at the time of a life-threatening diagnosis and other core elements including a multidimensional assessment to identify, prevent, and alleviate suffering; interdisciplinary team evaluation and treatment in selected cases; effective communication skills

Effects of a Palliative Care Intervention on Clinical Outcomes in Patients With Advanced Cancer

The Project ENABLE II Randomized Controlled Trial

Marie Bakitas, DNSc, APRN

Context There are few randomized controlled trials on the effectiveness of pallia-

2009, JAMA 302;7:741-749

- Early PC: telephone problem-solving intervention by APNs
- 322 pts, newly-diagnosed advanced GI, GU, lung, breast cancer
- prognosis of one year
- outcomes FACIT-Pal*, ESAS, CES-D (every 3 months)

- Results: improved QOL, mood, but not symptom intensity or reduced days in hospital, ICU, emergency department

Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer

Jennifer S. Temel, M.D., Joseph A. Greer, Ph.D., Alona Muzikansky, M.A., Emily R. Gallagher, R.N., Sonal Admane, M.B., B.S., M.P.H., Vicki A. Jackson, M.D., M.P.H., Constance M. Dahlin, A.P.N., Craig D. Blinderman, M.D., Juliet Jacobsen, M.D., William F. Pirl, M.D., M.P.H., J. Andrew Billings, M.D., and Thomas J. Lynch, M.D.

ABSTRACT

BACKGROUND

Patients with metastatic non–small-cell lung cancer have a substantial symptom burden and may receive aggressive care at the end of life. We examined the effect of introducing palliative care early after diagnosis on patient-reported outcomes and end-of-life care among ambulatory patients with newly diagnosed disease.

METHODS

We randomly assigned patients with newly diagnosed metastatic non–small-cell lung cancer to receive either early palliative care integrated with standard oncologic care or standard oncologic care alone. Quality of life and mood were assessed at baseline and at 12 weeks with the use of the Functional Assessment of Cancer

Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer

- Early PC: palliative care team (MD and APN)
- 151 pts, newly-diagnosed advanced non-small cell lung cancer
- ECOG 0, 1, 2
- Outcomes: FACT-Lung*, HADS, PHQ-9 at 12 weeks

- Results: improved QOL, mood; longer survival (11.6 vs. 8.9 months), despite less aggressive treatment

Early palliative care for patients with advanced cancer: a cluster-randomised controlled trial

Camilla Zimmermann, Nadia Swami, Monika Krzyzanowska, Breffni Hannon, Natasha Leighl, Amit Oza, Malcolm Moore, Anne Rydall, Gary Rodin, Ian Tannock, Allan Donner, Christopher Lo

Summary

Background Patients with advanced cancer have reduced quality of life, which tends to worsen towards the end of life. We assessed the effect of early palliative care in patients with advanced cancer on several aspects of quality of life.

Methods The study took place at the Princess Margaret Cancer Centre (Toronto, ON, Canada), between Dec 1, 2006, and Feb 28, 2011. 24 medical oncology clinics were cluster randomised (in a 1:1 ratio, using a computer-generated sequence, stratified by clinic size and tumour site [four lung, eight gastrointestinal, four genitourinary, six breast, two gynaecological]), to consultation and follow-up (at least monthly) by a palliative care team or to standard cancer care. Complete masking of interventions was not possible; however, patients provided written informed consent to participate in their own study group, without being informed of the existence of another group. Eligible patients had advanced cancer, European Cooperative Oncology Group performance status of 0–2, and a clinical prognosis of 6–24 months. Quality of life (Functional Assessment of Chronic Illness Therapy—Spiritual Well-Being [FACIT-Sp] scale and Quality of Life at the End of Life [QUAL-E] scale), symptom severity (Edmonton Symptom Assessment System [ESAS]), satisfaction with care (FAMCARE-P16), and problems with medical interactions (Cancer Rehabilitation Evaluation System Medical Interaction Subscale [CARES-MIS]) were measured at baseline and monthly for 4 months. The primary outcome was change score for FACIT-Sp at 3 months. Secondary endpoints included change score for FACIT-Sp at 4 months and change scores for other scales at 3 and 4 months. This trial is registered with ClinicalTrials.gov, number NCT01248624.

Findings 461 patients completed baseline measures (228 intervention, 233 control); 393 completed at least one follow-up assessment. At 3-months, there was a non-significant difference in change score for FACIT-Sp between intervention and control groups (3·56 points [95% CI –0·27 to 7·40], p=0·07), a significant difference in QUAL-E (2·25 [0·01 to 4·49], p=0·05) and FAMCARE-P16 (3·79 [1·74 to 5·85], p=0·0003), and no difference in ESAS (–1·70 [–5·26 to 1·87], p=0·33) or CARES-MIS (–0·66 [–2·25 to 0·94], p=0·40). At 4 months, there were significant differences in change scores for all outcomes except CARES-MIS. All differences favoured the intervention group.

Interpretation Although the difference in quality of life was non-significant at the primary endpoint, this trial shows promising findings that support early palliative care for patients with advanced cancer.

Lancet 2014; 383: 1721–30

Published Online
February 19, 2014
http://dx.doi.org/10.1016/S0140-6736(13)62416-2

See Comment page 1699

See Online for video

Division of Medical Oncology and Haematology, Department of Medicine (C Zimmermann MD, M Krzyzanowska MD, B Hannon MBChB, N Leighl MD, Prof A Oza MD [Lon], Prof M Moore MD, Prof I Tannock MD), **and Department of Psychiatry** (C Zimmermann, Prof G Rodin MD, C Lo PhD), **University of Toronto, Toronto, ON, Canada; Department of Psychosocial Oncology and Palliative Care** (C Zimmermann, N Swami BSc, B Hannon, A Rydall MSc, Prof G Rodin, C Lo), **Department of Medical Oncology** (M Krzyzanowska, N Leighl, Prof A Oza, Prof M Moore, Prof I Tannock), **and Campbell Family Cancer Research Institute** (C Zimmermann, Prof G Rodin, Prof I Tannock), **Princess**

THE LANCET
2014; 383: 1721–30

Early palliative care for patients with advanced cancer: a cluster-randomised controlled trial

Camilla Zimmermann, Nadia Swami, Monika Krzyzanowska, Breffni Hannon, Natasha Leighl, Amit Oza, Malcolm Moore, Anne Rydall, Gary Rodin, Ian Tannock, Allan Donner, Christopher Lo

- Early pc: palliative care team (MD and nurse)
- 461 patients, GU, GI, breast, gyne, lung cancer
- prognosis 6-24 mo, ECOG 0,1,2
- Outcomes: FACIT-Sp*, QUAL-E, FAMCARE-P, ESAS, CARES-MIS

- Results: improved QOL (QUAL-E at 3 mo, both at 4 mo), satisfaction with care (3 and 4 mo), symptom control (4 mo)

Further EPC trials

- Bakitas et al. J Clin Oncol 2015 (early vs delayed pc)
- Maltoni et al. Eur J Cancer 2016 (pancreatic cancer: early vs “on demand” pc)*
- El-Jawahri et al. JAMA 2016 (hematological cancers, hospitalized for stem cell transplantation)*
- Temel et al. J Clin Oncol 2017 (non-colon GI, lung)*
- Groenvold et al. Palliat Med 2017 (early pc vs. standard care)

Palliative Medicine
2017, Vol. 31(9) 814–824
© The Author(s) 2017
Reprints and permissions:
sagepub.co.uk/journalsPermissions.nav
DOI: 10.1177/0269216317705100
journals.sagepub.com/home/pmj
SAGE

Randomised clinical trial of early specialist palliative care plus standard care versus standard care alone in patients with advanced cancer: The Danish Palliative Care Trial

Abstract

Background: Beneficial effects of early palliative care have been found in advanced cancer, but the evidence is not unequivocal.

Aim: To investigate the effect of early specialist palliative care among advanced cancer patients identified in oncology departments.

Setting/participants: The Danish Palliative Care Trial (DanPaCT) (ClinicalTrials.gov NCT01348048) is a multicentre randomised clinical trial comparing early referral to a specialist palliative care team plus standard care versus standard care alone. The planned sample size was 300. At five oncology departments, consecutive patients with advanced cancer were screened for palliative needs. Patients with scores exceeding a predefined threshold for problems with physical, emotional or role function, or nausea/vomiting, pain, dyspnoea or lack of appetite according to the European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30) were eligible. The primary outcome was the change in each patient's primary need (the most severe of the seven QLQ-C30 scales) at 3- and 8-week follow-up (0–100 scale). Five sensitivity analyses were conducted. Secondary outcomes were change in the seven QLQ-C30 scales and survival.

Results: Totally 145 patients were randomised to early specialist palliative care versus 152 to standard care. Early specialist palliative care showed no effect on the primary outcome of change in primary need (−4.9 points (95% confidence interval −11.3 to +1.5 points); $p = 0.14$). The sensitivity analyses showed similar results. Analyses of the secondary outcomes, including survival, also showed no differences, maybe with the exception of nausea/vomiting where early specialist palliative care might have had a beneficial effect.

Conclusion: We did not observe beneficial or harmful effects of early specialist palliative care, but important beneficial effects cannot be excluded.

Randomised clinical trial of early specialist palliative care plus standard care versus standard care alone in patients with advanced cancer: The Danish Palliative Care Trial

Palliative Medicine
2017, Vol. 31(9) 814–824
© The Author(s) 2017
Reprints and permissions:
sagepub.co.uk/journalsPermissions.nav
DOI: 10.1177/0269216317705100
journals.sagepub.com/home/pmj
SAGE

- Early pc: palliative care team (MD and nurse)
- 297 patients with advanced cancer who exceeded screening threshold on EORTC QLQ-C30 scales
- Outcomes: EORTC QLQ-C30: *change in primary need (most severe of the 7 scales); change in each of 7 scales; survival
- Results: no change in primary need at 3 or 8 weeks; no difference in 7 scales except nausea/vomiting; no difference in survival

* primary outcome

DanPACT Results in more detail

Table 3. Results of the main analysis of the primary[a] and secondary outcomes measured by the EORTC QLQ-C30.

	Intervention			Control			Mean weighted change[b] (95% CI)	p
	Baseline, mean (SD)	3 weeks, mean (SD)	8 weeks, mean (SD)	Baseline, mean (SD)	3 weeks, mean (SD)	8 weeks, mean (SD)		
Primary outcome[a] (range: 0–100; worst score 100)	75.5 (22.7)	53.8 (29.7)	50.7 (29.6)	74.3 (17.3)	56.5 (27.5)	55.4 (29.9)	−4.9 (−11.3; 1.6)	0.14
Secondary outcomes								
Function scales (range: 0–100; worst score 0)								
Physical function	57.5 (19.6)	59.1 (22.8)	57.6 (22.3)	58.8 (19.3)	60.2 (21.0)	59.9 (22.5)	−0.4 (−4.0; 3.2)	0.84
Role function	36.8 (25.0)	42.7 (29.7)	46.9 (30.4)	41.8 (27.0)	47.0 (27.9)	45.7 (30.4)	2.1 (−3.9; 8.1)	0.48
Emotional function	67.8 (22.4)	69.6 (23.1)	73.0 (21.4)	66.7 (22.1)	72.2 (22.4)	70.1 (22.7)	−1.6 (−5.7; 2.5)	0.45
Symptom scales (range 0–100, worst score 100)								
Pain	35.5 (30.2)	29.4 (28.7)	31.4 (30.0)	34.2 (26.0)	30.5 (27.3)	35.0 (30.8)	−3.4 (−9.5; 2.6)	0.27
Dyspnoea	41.6 (33.8)	35.4 (35.2)	36.5 (32.5)	39.8 (33.4)	38.0 (32.7)	38.7 (31.0)	−4.2 (−10.6; 2.3)	0.20
Nausea/vomiting	17.1 (24.1)	9.5 (15.4)	8.9 (15.6)	17.6 (18.1)	15.2 (18.8)	14.8 (22.6)	−5.8 (−10.3; −1.2)	0.013
Lack of appetite	30.5 (34.7)	24.8 (30.6)	22.6 (29.3)	38.0 (33.5)	33.8 (32.0)	31.7 (35.4)	−2.0 (−8.9; 4.9)	0.57

EPC Trials: Summary

Outcomes	Bakitas et al, 2009	Temel et al, 2012	Zimmermann et al, 2014	Bakitas et al, 2015	Maltoni et al, 2016	Temel et al, 2017	Groenvold et al, 2017
QOL	+	+	+	=	+	+	=
Physical Symptoms	=	na	+	=	na	na	=/+ (nausea)
Depression	+	+	na	=	=	+	=
Patient satisfaction	na	na	+	na	=	na	na
Caregiver outcomes	= burden	na	+ satisfaction = QOL	+ depression = QOL	na	+ depression =/+ QOL	na
EOL care/ service use	=	+	na	=	+/=	na	na
Survival	=	+	na	+	na	na	=

JAMA | Original Investigation

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
  - No association between palliative care and survival
- Narrative synthesis
  - Palliative care consistently associated with improvements in advance care planning, patient and caregiver satisfaction, and lower health care utilization

ASCO Clinical Guideline

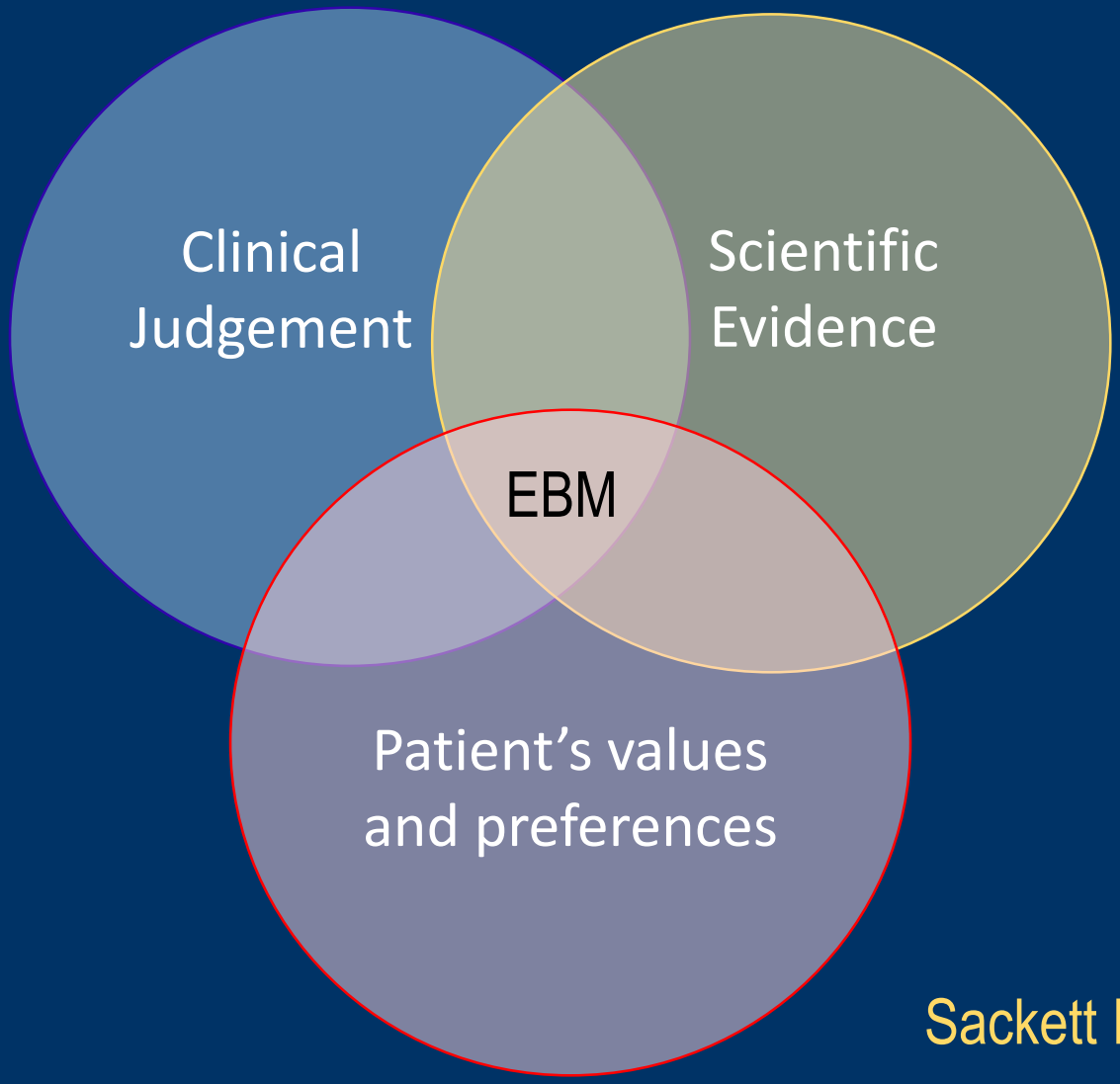
Combined standard oncology care and palliative care should be considered early in the course of illness for any patient with metastatic cancer and/or high symptom burden.

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 2017

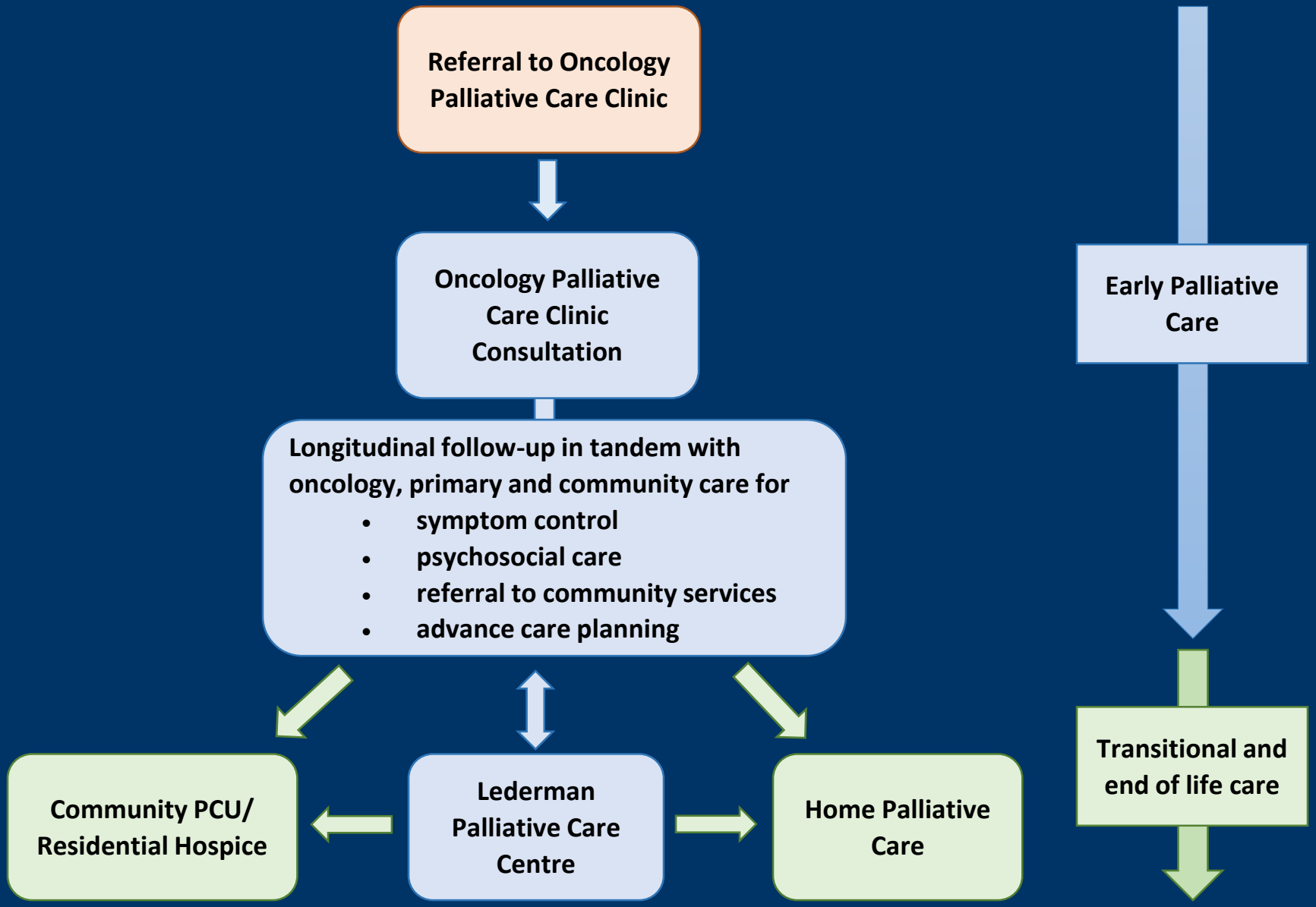
What is evidence-based medicine?



Sackett D, BMJ, 1996

Tertiary palliative care pathway for PM

(Hannon et al, Support Care Cancer 2015)



Qualitative study: Patient/caregiver experiences

- Prompt, personalized symptom management
  - *" You're never panicked really about the pain, because you know you've got somebody there that's going to help you deal with it "*
- Holistic support of patients and caregivers
  - *" Well I can say anything pretty well to [palliative care physician], I can say anything -- if something is really bothering me, I can say it to her. "*
- Guidance in decision-making
  - *" …because there are many things that happened to [her] along the way that maybe her and I together might not have been able to deal with unless we had his knowledge, or his expertise, or his suggestion or advice"*
- Preparation for the future
  - *" It's just such an unknown and to have it explained as nicely as it was by [palliative care physician], so it was very good "*

Hannon et al. Palliat Med. 2016

*40 patients and caregivers in EPC intervention arm

Qualitative study: Patient/caregiver experiences

- Prompt, personalized symptom management
  - *" You're never panicked really about the pain, because you know you've got somebody there that's going to help you deal with it "*
- Holistic support of patients and caregivers
  - *" Well I can say anything pretty well to [palliative care physician], I can say anything -- if something is really bothering me, I can say it to her. "*
- Guidance in decision-making
  - *" ...because there are many things that happened to [her] along the way that maybe her and I together might not have been able to deal with unless we had his knowledge, or his expertise, or his suggestion or advice"*
- Preparation for the future
  - *" It's just such an unknown and to have it explained as nicely as it was by [palliative care physician], so it was very good "*

Hannon et al. Palliat Med. 2016

*40 patients and caregivers in EPC intervention arm

Qualitative study: Patient/caregiver experiences

- Prompt, personalized symptom management
  - *" You're never panicked really about the pain, because you know you've got somebody there that's going to help you deal with it "*
- Holistic support of patients and caregivers
  - *" Well I can say anything pretty well to [palliative care physician], I can say anything -- if something is really bothering me, I can say it to her. "*
- Guidance in decision-making
  - *" ...because there are many things that happened to [her] along the way that maybe her and I together might not have been able to deal with unless we had his knowledge, or his expertise, or his suggestion or advice"*
- Preparation for the future
  - *" It's just such an unknown and to have it explained as nicely as it was by [palliative care physician], so it was very good "*

Hannon et al. Palliat Med. 2016

*40 patients and caregivers in EPC intervention arm

Qualitative study: Patient/caregiver experiences

- Prompt, personalized symptom management
  - *" You're never panicked really about the pain, because you know you've got somebody there that's going to help you deal with it "*
- Holistic support of patients and caregivers
  - *" Well I can say anything pretty well to [palliative care physician], I can say anything -- if something is really bothering me, I can say it to her. "*
- Guidance in decision-making
  - *" ...there are many things that happened to [patient] along the way that maybe her and I together might not have been able to deal with unless we had [pc physician's] knowledge, or his expertise, or his suggestion or advice"*
- Preparation for the future
  - *" It's just such an unknown and to have it explained as nicely as it was by [pc physician], so it was very good "*

Hannon et al. Palliat Med. 2016

*40 patients and caregivers in EPC intervention arm

Perception of oncologist vs. pc roles

Category	Oncology theme	EPC Theme
Focus of care	Cancer control, disease-focused care	Symptom control, holistic, family-focused care
Care delivery	Structured, time-limited visits based on protocol	Flexible, personalized, unstructured visits
Complementary care (intervention group)	***I do see them as different.*** **I think [oncologist] is there…He's the guy who's mapping the way.** He's saying, "Okay, these tests and based on my experience and my understanding of this disease indicates that we should go this way (…)" **[Palliative care physician]'s role is** (…) being there just as another ear and **looking at you from a more holistic perspective, as a whole person.** So ***I think they're both necessary and I think they're both really beneficial.***	

Hannon et al, Oncologist 2016

* 71 interviews with patients and caregivers

Barriers to implementing early palliative care

- Public and professional misconceptions
- Workforce
  - Palliative care physicians in short supply
  - Insufficient training in palliative care – medical school and residency
- Inequitable access
  - Patients who need palliative care are not necessarily those who receive it
  - Wide differences within nations and regions

Ahmed et al. Palliat Med, 2004
Report on Palliative Care, Auditor General of Ontario, 2014
Knaul et al. Lancet, 2017

VOLUME 30 · NUMBER 35 · DECEMBER 10 2012

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%
- 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

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

Perceptions of palliative care

- Initial perceptions:
  - "Death", "plots waiting", "end of the road", preparing to die", "nothing to be done", "no hope left", "places that you never get out of again"
- Sources of perceptions:
  - Medical system and media
- After receiving early palliative care:
  - Broadened understanding, deep appreciation for care, but still uncomfortable with term "palliative"
- Reframing and/or renaming palliative care:
  - "That shell of meaning that surrounds palliative care has to somehow change…"
  - "I think you have to think about a name outlining what you're trying to do…"

Zimmermann et al. CMAJ 2016

*71 patients/caregivers participating in EPC trial

Mixed Messages about Palliative Care



Planning your palliative care:

A booklet to help you get ready to leave the hospital

UHN

Patient Education

Improving health through education





Primary PC: Family Physician involvement

- Wide range of involvement internationally in palliative care
  - UK, Netherlands, Australia: 75-85% of GPs involved in palliative care
  - Canada, Denmark, Japan: <50% of family physicians/GPs provide palliative care
- Varies by setting
  - Urban – low level of involvement, with frequent sign-over to specialized services
  - Rural – most family physicians provide palliative care

Rubin et al, The expanding role of primary care in cancer control. Lancet Oncol, 2015

Survey of GPs/FPs in Central LHIN

- 295 surveys (response rate 22%)
  - 34% engaged in some home palliative care
    - Median monthly caseload 2 patients
  - 26% engageable, 40% not engageable

- Engageable: younger, placed greater value on better remuneration
- Nonengageable: barriers = time, interest in home pc and emotional concerns about death/dying

Malik et al, J Palliat Care, 2017

Representative Skill Sets for Primary and Specialty Palliative Care.

Primary Palliative Care

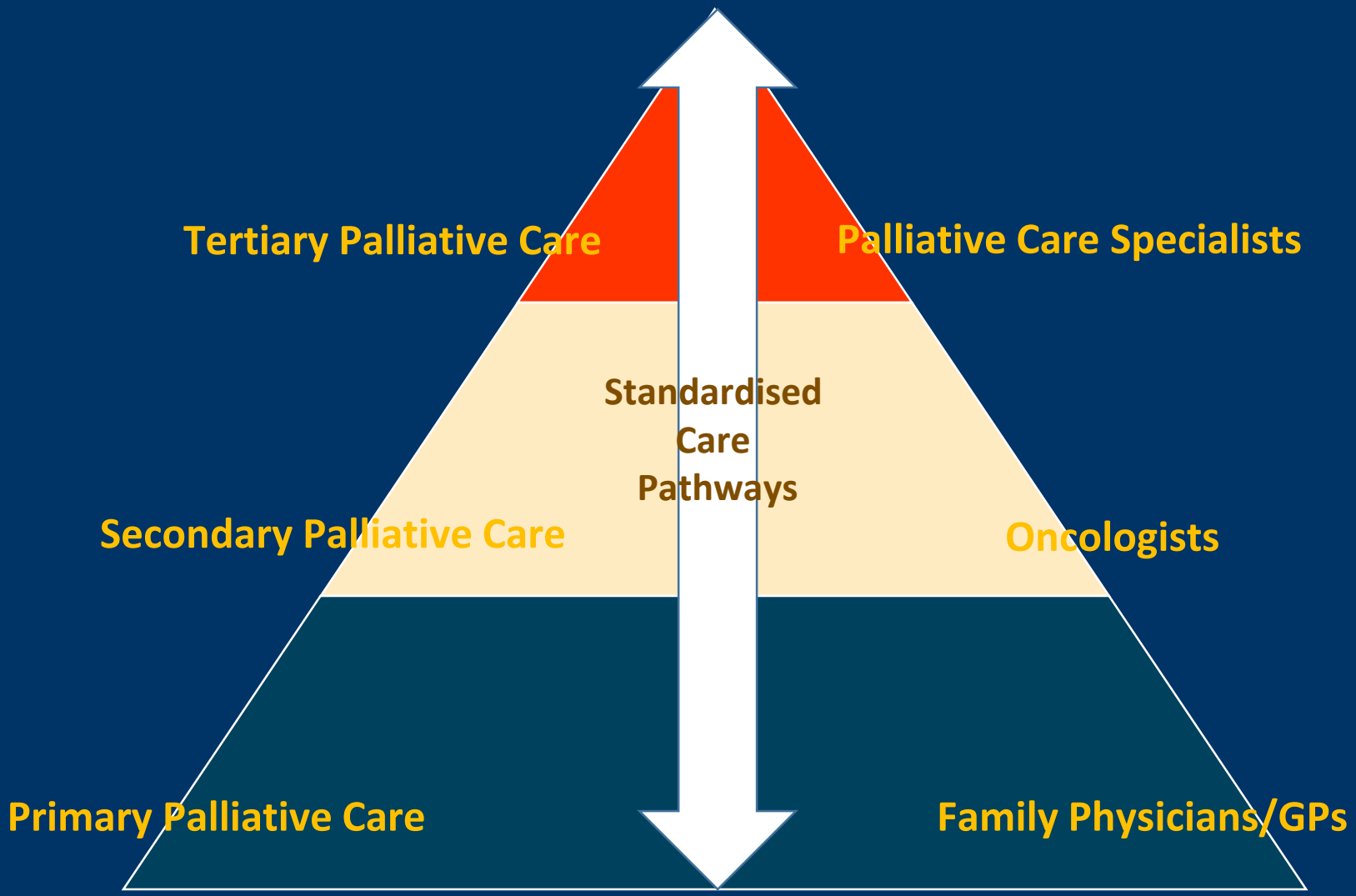
- Basic management of pain and symptoms
- Basic management of depression and anxiety
- Basic discussions about
  - Prognosis
  - Goals of treatment
  - Suffering
  - Code status

Specialty Palliative Care

- Management of refractory pain or other symptoms
- Management of more complex depression, anxiety, grief, and existential distress
- Assistance with conflict resolution regarding goals or methods of treatment
  - Within families
  - Between staff and families
  - Among treatment teams
- Assistance in addressing cases of near futility

Quill and Abernathy. Generalist plus specialist palliative care - Creating a more sustainable model. N Engl J Med 2013

Integrating oncology palliative care



Are we there yet?

- Sufficient evidence to demonstrate benefits of early palliative care in the outpatient oncology setting
- Trials tend to be in tertiary care settings, with specialized palliative care teams

Ongoing trials

- ClinicalTrials.gov: “early palliative care”
  - 94 entries (45 North America, 28 Europe)
  - Other countries: Brazil, China, South Korea, Rwanda
  - + 7 in Australia from ANZCTR
  - Cancer: Lung, GI, Esophageal, HCC, Gastric/pancreatic, Stem cell transplant, Gynaecologic, Breast, Leukemia
  - Non-cancer: COPD, cirrhosis, renal failure, CHF, HIV

Further research needed

- Other models of early palliative care (primary, secondary)
- Identifying high-need patients who should receive tertiary palliative care: e.g. by referral guidelines, symptom-screening, prognostic modeling, or other means
- Trials specifically assessing economic cost at system and patient/family level

Tak!

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



