Early palliative care for patients with solid tumours and haematologic malignancies

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fondazione GIMEMA onlus
per la promozione e lo sviluppo della ricerca scientifica sulle malattie ematologiche. FRANCO MANDELLI

Si ringrazia per il supporto

Con il patrocinio di

SIE Società Italiana di Ematologia

LE CURE PALLIATIVE PRECOCI IN
EMATO-ONCOLOGIA:
la nuova risposta ai bisogni di pazienti e caregivers

19 maggio 2023 **Roma**, Hotel Donna Camilla Savelli

Disclosures of Camilla Zimmermann – No Disclosures

Company name	Research support	Employee	Consultant	Stockholder	Speakers bureau	Advisory board	Other

Objectives

- To review the **evidence** for early palliative care integration in solid tumours and haematologic malignancies (HM)
- To describe the **current state** of palliative care involvement in solid tumours and HM
- To discuss **barriers** to early palliative care involvement in solid tumours and HM

Evidence for early integration

Definition of Palliative Care

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.

WHO, 2002

JAMA®

Online article and related content current as of May 5, 2009.

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**

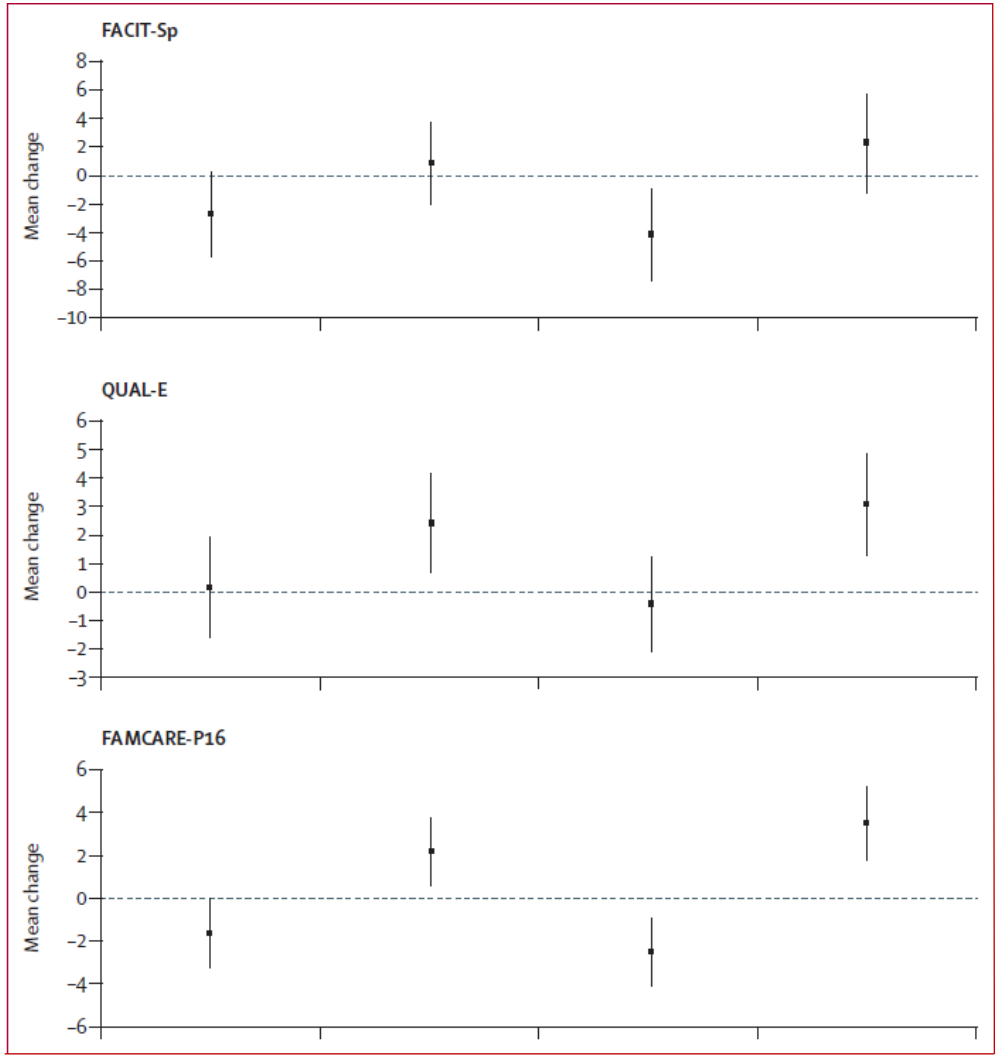
THE LANCET
2014; 383: 1721–30

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, 5 tumour sites: GU, GI, Breast, Gyne, Lung 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, FACIT-Sp and QUAL-E at 4 mo), satisfaction with care (3 and 4 mo) and symptom control (4 mo)



Early palliative care for patients with solid tumours

First Author	Bakitas JAMA 2009	Temel NEJM 2010	Zimmermann Lancet 2014	Bakitas J Clin Oncol 2015	Maltoni Eur J Cancer 2016	Temel J Clin Oncol 2016	Groenvold Palliat Med 2017	Vanbutsele Lancet Oncol 2018	Scarpi Support Care Cancer 2019
Country	USA, n=322	USA, n=151	Canada, n=461	USA, n=207	Italy, n=207	USA, n=350	Denmark, n=297	Belgium, n=186	Italy, n=186
Definition of 'early'	Within 8-12 wk of diagnosis	Within 8 wk of diagnosis	6-24 mo clinical prognosis	With 1-2 mo of diagnosis, 6-24 mo prognosis	Within 8 wk of diagnosis, >2 mo prognosis	Within 8 wk of diagnosis	Symptom/prob. (EORTC-QLQ-C30); "earlier"	Within 12 wk of diagnosis, 12 mo prognosis	Within 8 wks of dx, >2 mo prognosis
Setting	Telehealth	Outpatient, embedded	Outpatient, freestanding	Telehealth	Outpatient, free-standing	Outpatient, embedded	Outpatient and telehealth	Outpatient and inpatient	Outpatient
QOL	+	+	+	=	+	+	=	+	=
Physical Symptoms	=	+	+	=	+	n/a	=/+ (nausea)	=	=
Depression	+	+	n/a	=	=	+	=	=	=
Satisfaction with care	n/a	n/a	+	n/a	=	n/a	n/a	n/a	=
Caregiver outcomes	= burden	n/a	+satisfaction = QOL	+ mood = QOL	n/a	+ mood =/+ QOL	n/a	n/a	=
EOL care/ service use	=	+	n/a	=	+/=	n/a	n/a	n/a	n/a
Survival	=	+	n/a	+	n/a	n/a	=	=	=

Early palliative care for patients with solid tumours

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Physical Symptoms	=	+	+	=	+	n/a	=/+ (nausea)	=	=
Depression	+	+	n/a	=	=	+	=	=	=
Satisfaction with care	n/a	n/a	+	n/a	=	n/a	n/a	n/a	=
Caregiver outcomes	= burden	n/a	+satisfaction = QOL	+ mood = QOL	n/a	+ mood =/+ QOL	n/a	n/a	=
EOL care/ service use	=	+	n/a	=	+/=	n/a	n/a	n/a	n/a
Survival	=	+	n/a	+	n/a	n/a	=	=	=

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

Cochrane Library

Cochrane Database of Systematic Reviews

Early palliative care for adults with advanced cancer (Review)

Haun MW, Estel S, Rücker G, Friederich HC, Villalobos M, Thomas M, Hartmann M

RESEARCH

OPEN ACCESS

Effect of specialist palliative care services on quality of life in adults with advanced incurable illness in hospital, hospice, or community settings: systematic review and meta-analysis

Jan Gaertner,[1,2] Waldemar Siemens,[1] Joerg J Meerpohl,[3,4] Gerd Antes,[3] Cornelia Meffert,[1] Carola Xander,[1] Stephanie Stock,[5] Dirk Mueller,[5] Guido Schwarzer,[6] Gerhild Becker[1]

WHAT THIS STUDY ADDS

Integration of specialised palliative care was associated with a small effect on quality of life

The effect was most pronounced for patients with cancer and for those who received specialised care early

Lancet Oncology Commission

Integration of oncology and palliative care: a *Lancet Oncology* Commission

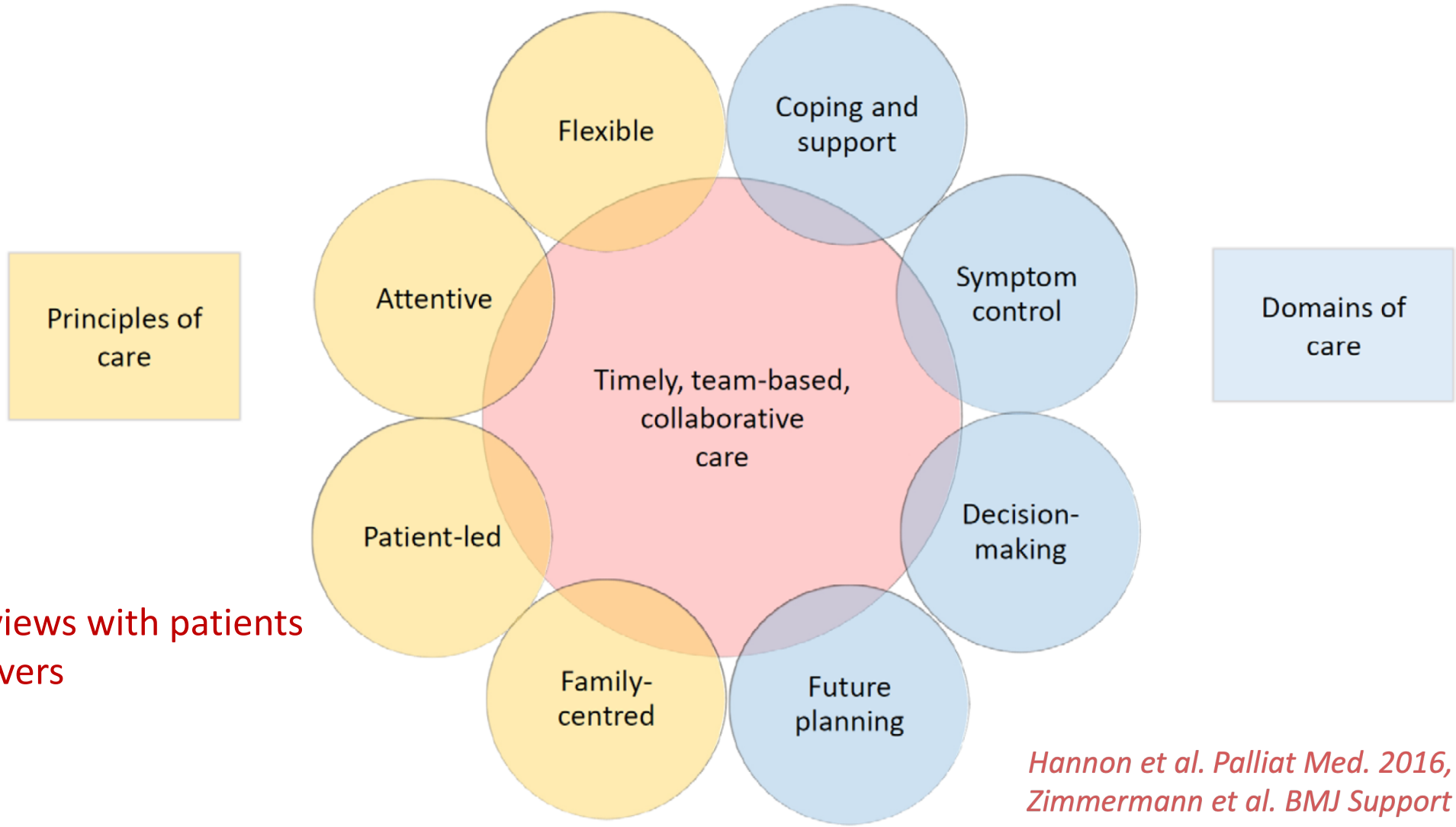
Stein Kaasa, Jon H Loge*, Matti Aapro, Tit Albreht, Rebecca Anderson, Eduardo Bruera, Cinzia Brunelli, Augusto Caraceni, Andrés Cervantes, David C Currow, Luc Deliens, Marie Fallon, Xavier Gómez-Batiste, Kjersti S Grotmol, Breffni Hannon, Dagny F Haugen, Irene J Higginson, Marianne J Hjermstad, David Hui, Karin Jordan, Geana P Kurita, Philip J Larkin, Guido Miccinesi, Friedemann Nauck, Rade Pribakovic, Gary Rodin, Per Sjøgren, Patrick Stone, Camilla Zimmermann, Tonje Lundeby*

CA CANCER J CLIN 2018;68:356–

Improving Patient and Caregiver Outcomes in Oncology: Team-Based, Timely, and Targeted Palliative Care

David Hui, MD, MSc[1,*]; Breffni L. Hannon, MBChB[2]; Camilla Zimmermann, MD, PhD[3]; Eduardo Bruera, MD, FAAHPM[4]

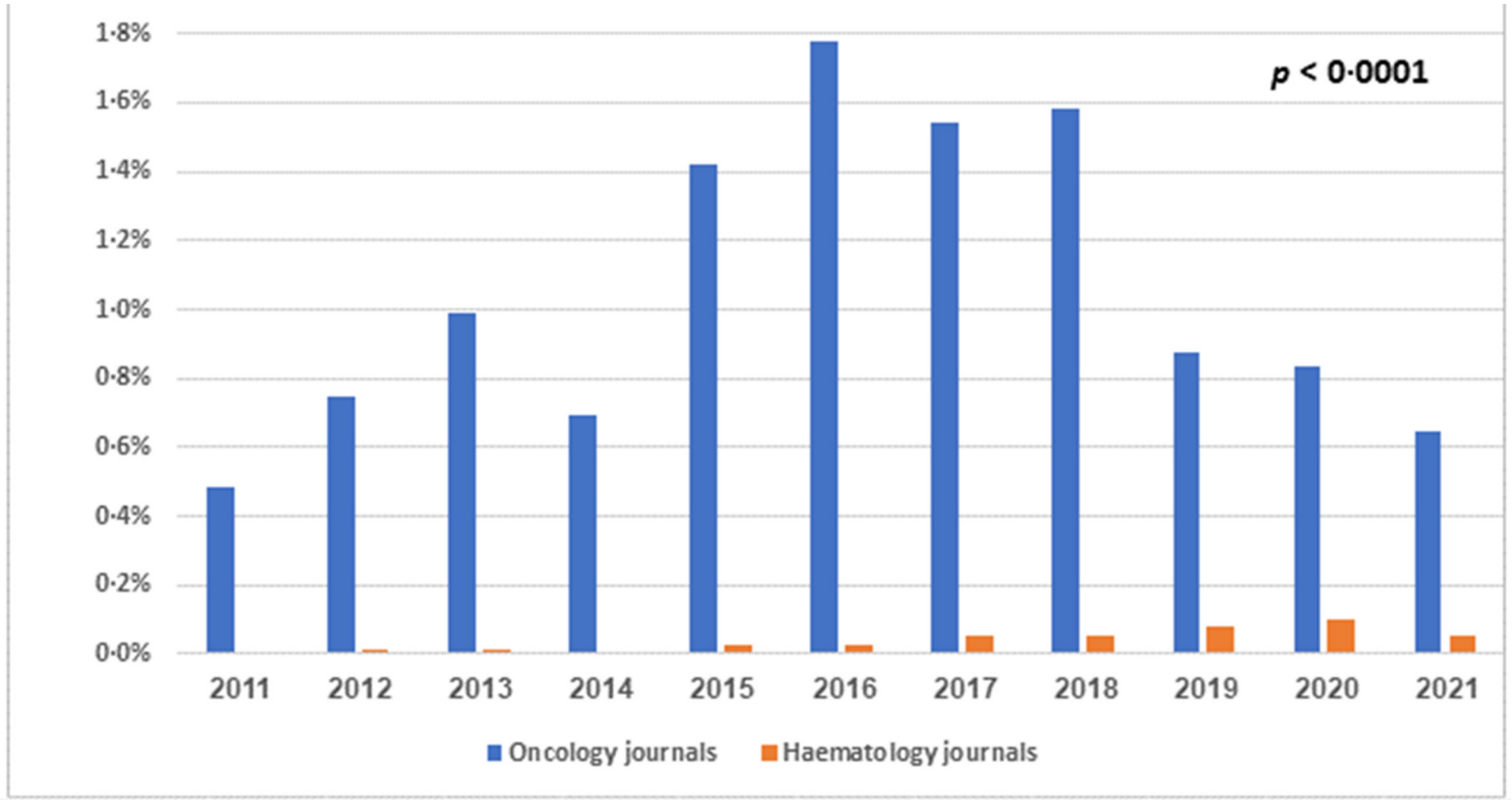
Principles and Domains of Early Palliative Care



* 71 interviews with patients and caregivers

Hannon et al. Palliat Med. 2016, Oncologist 2016; Zimmermann et al. BMJ Support Palliat Care 2019

Palliative Care Publications: % of total in 5 leading solid tumour vs HM journals



JOURNAL	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020	2021
Oncology	0·48%	0·75%	0·99%	0·69%	1·42%	1·78%	1·54%	1·58%	0·88%	0·83%	0·65%
Haematology	0%	0·01%	0·02%	0·00%	0·03%	0·03%	0·05%	0·06%	0·08%	0·10%	0·05%

Shaulov et al. Br J Haematol 2022

Early palliative care for patients with HM

First Author	El Jawahri JAMA 2016, J Clin Oncol 2017	El Jawahri JAMA Onol 2021	Rodin Support Care Cancer 2020
Country, Population	USA, Receiving allo/auto stem cell transplant	USA, High risk AML receiving intensive chemo	Canada, Newly-diagnosed/recently relapsed AL
Clinician	PC physician or APN	PC physician, APN or physician assistant	Therapist trained in EASE-Psy Specialized PC physician and nurse
Definition of 'early'	Within 72h of admission for transplantation	Within 72h of receiving intensive chemotx	EASE-psy – within 1 mo of admission EASE-pal – triggered by ESAS-AL
Setting	Inpatient	Inpatient	Inpatient
QOL	+ (week 2*, month 3) = (month 6)	+ (week 2* through week 24)	=
Physical Symptoms	+ symptom burden (week 2) = symptom burden (month 3) = fatigue (week 2, month 3)	=	pain (= week 4, = week 8, + week 12)
Depression, anxiety	+ depression (weeks 2, 3; month 6) anxiety (+ week 2, = month 3, month 6)	+ depression (week 2 through week 24) + anxiety (week 2 through week 24)	= weeks 4, 8, 12
Traumatic stress, PTSD	+ (month 6)	+ (week 2 through week 24)	+ week 4, = week 8, + week 12
Caregiver outcomes	+ depression (week 2) = QOL, anxiety (week 2)	n/a	n/a
EOL care/ service use	n/a	+ EOLc preference discussion, chemo at EOL; = hospice use, length of stay, hospitalization at EOL	n/a

TABLE 3 Ongoing early palliative care clinical trials in patients with haematologic malignancies[b]

[Principal Investigator]; status; phase; setting	Country; year registered	Patients; Cancer diagnosis	Intervention			Outcomes[a]
			Comparison group	Clinician providing PC	Timing of early PC	
[El-Jawahri] Active, not recruiting N/A inpatient	NCT02975869 USA 2016	>60 years old: -High risk AML	Standard leukaemia care	Collaborative PC and leukaemia specialist	Newly diagnosed, relapsed, primary refractory	**QOL**, psychological distress, symptom burden, PTSD, EOL discussion preference, chemotherapy within 30 days of death, admission within 7 days of death, hospice utilization
[El Chaer] Recruiting Phase II; Inpatient and outpatient	NCT04482894 USA 2020	≥18 years old: -AML, ALL, MDS, CMML	Standard care with referral upon request	PC specialist	Newly diagnosed, relapsed, primary refractory	**Place of death**, survival, duration, admissions duration/type/ frequency, ER visits, hospice service use, transfusions, QOL, code status change, GOC discussions
[Samala] Recruiting Phase II Outpatient	NCT04248244 USA 2020	≥18 years old: -MM	No comparison group	Specialized physician, APN, care coordinators	Within 8 weeks of diagnosis	**QOL, anxiety, depression, health care utilization**
[Tanzi][102] Unknown Phase II Outpatient	NCT03743480 Italy 2020	≥18 years old: -Incurable haematological tumour and last line of therapy	Standard care with referral upon request	Integrated PC team	Soon after decision of last active treatment	**Adherence to palliative care program**, QOL, anxiety, depression, PPS.
[Rodin & Zimmermann] Recruiting Inpatient & outpatient & telephone	NCT04224974 Canada 2020	≥18 years old: Newly diagnosed AML and ALL	Standard care with referral upon request	-Supportive psychotherapy: trained therapist -Symptom triggered referral: PC specialists	Within 2 weeks of admission for treatment of acute leukaemia	**Traumatic stress symptoms, physical symptom severity**, QOL, ASD, depression, satisfaction with care, pain, survival, quality adjusted life years
[Booker] Not yet recruiting N/A Virtually (phone or zoom)	NCT05190653 Canada 2022	≥18 years old: -Haematologic malignancy -Family caregiver	Standard care with referral upon request	PC nurse practitioner or physician	Scheduled for SCT	**QOL**, symptom burden, patient and caregiver prognostic understanding, caregiver QOL
[Scarfò][103] Recruiting Open label Virtually (App)	NCT04370457 Italy 2020	≥ years old: -CLL/SLL or MDS -Users of internet connected device	Standard care with PC if needed	MyPal ePRO: PROs at baseline, monthly times 6, and at 12 months	Scheduled to receive any line of therapy for CLL/SLL or MDS	**QOL**
[Guastella] Recruiting Phase III Not specified	NCT03800095 France 2019	≥70 years old: -AML, MDS, diffuse large B cell lymphoma	Standard care with referral upon request	Palliative and supportive care team	At diagnosis in AML, MDS; after 3rd line therapy in lymphoma	**QOL**, symptoms, survival, satisfaction with care, cost effectiveness

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Shaulov et al. Br J Haematol 2022

Current state of palliative care involvement

Integration of Palliative Care Into Standard Oncology Care: American Society of Clinical Oncology Clinical Practice Guideline Update

Betty R. Ferrell, Jennifer S. Temel, Sarah Temin, Erin R. Alesi, Tracy A. Balboni, Ethan M. Basch, Janice I. Firn, Judith A. Paice, Jeffrey M. Peppercorn, Tanyanika Phillips, Ellen L. Stovall,† Camilla Zimmermann, and Thomas J. Smith

Recommendations

Inpatients and outpatients with advanced cancer should receive dedicated palliative care services, early in the disease course, concurrent with active treatment. Referral of patients to interdisciplinary palliative care teams is optimal, and services may complement existing programs. Providers may refer family and friend caregivers of patients with early or advanced cancer to palliative care services.

J Clin Oncol 34.

Jordan *et al. BMC Medicine* (2020) 18:368
https://doi.org/10.1186/s12916-020-01829-x

BMC Medicine

RESEARCH ARTICLE Open Access

Duration of palliative care before death in international routine practice: a systematic review and meta-analysis

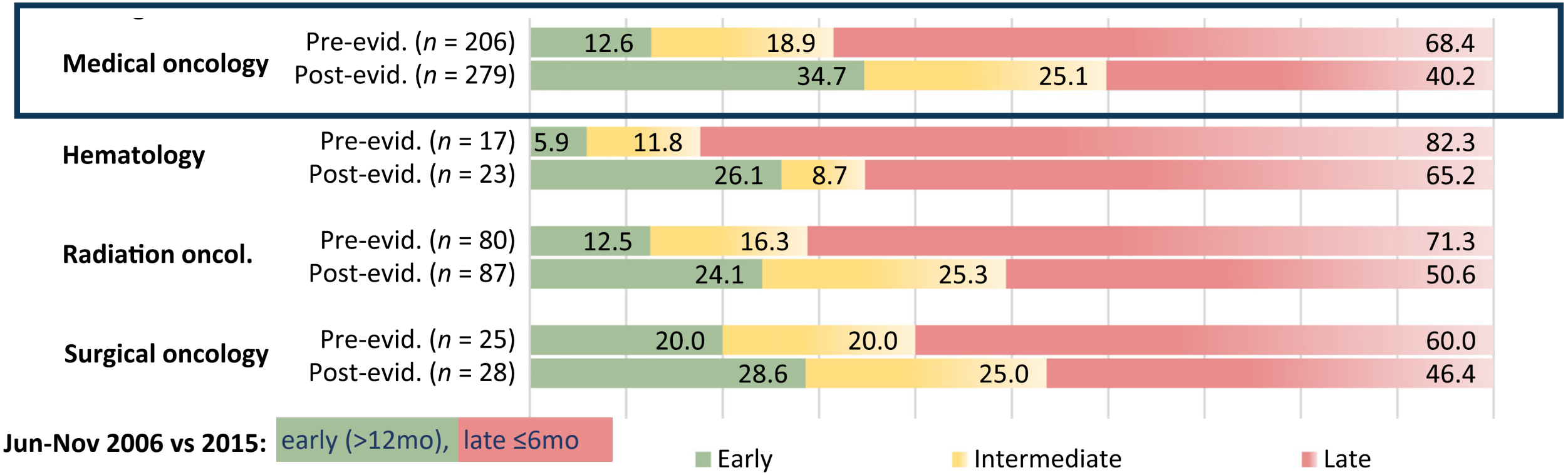
Roberta I. Jordan[1†], Matthew J. Allsop[1*†], Yousuf ElMokhallalati[1], Catriona E. Jackson[2], Helen L. Edwards[1], Emma J. Chapman[1], Luc Deliens[3,4] and Michael I. Bennett[1]

- 169 studies from 23 countries analysing >11 million patients
- Median duration from initiation of palliative care to death was 18.9 days

The Oncologist®

Timing of Palliative Care Referral Before and After Evidence from Trials Supporting Early Palliative Care

David Hausner,[b,d,h] Colombe Tricou,[b,d,i] Jean Mathews,[b,d] Deepa Wadhwa,[j] Ashley Pope,[d] Nadia Swami,[d] Breffni Hannon,[b,d] Gary Rodin,[c,d,g] Monika K. Krzyzanowska,[a,e] Lisa W. Le,[f] Camilla Zimmermann [b,c,d,g]



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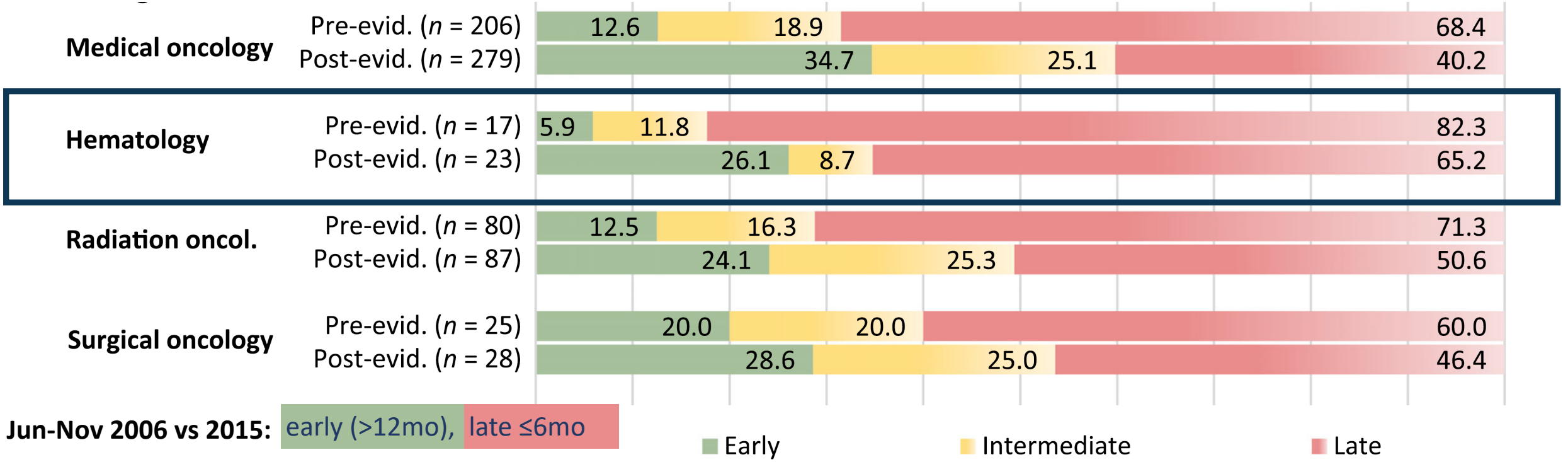
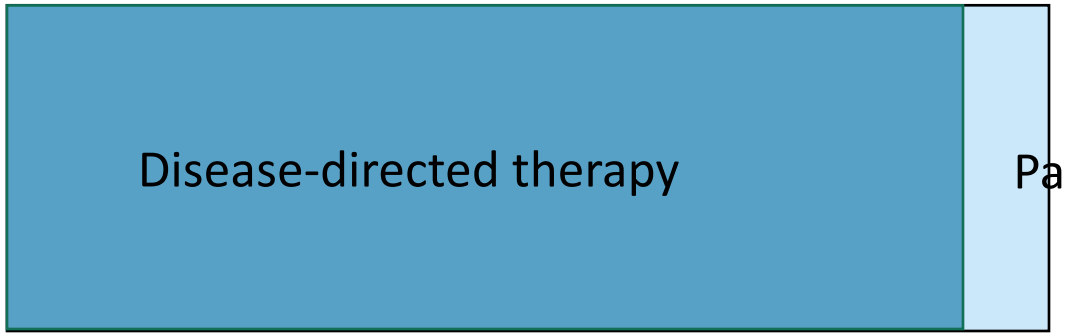
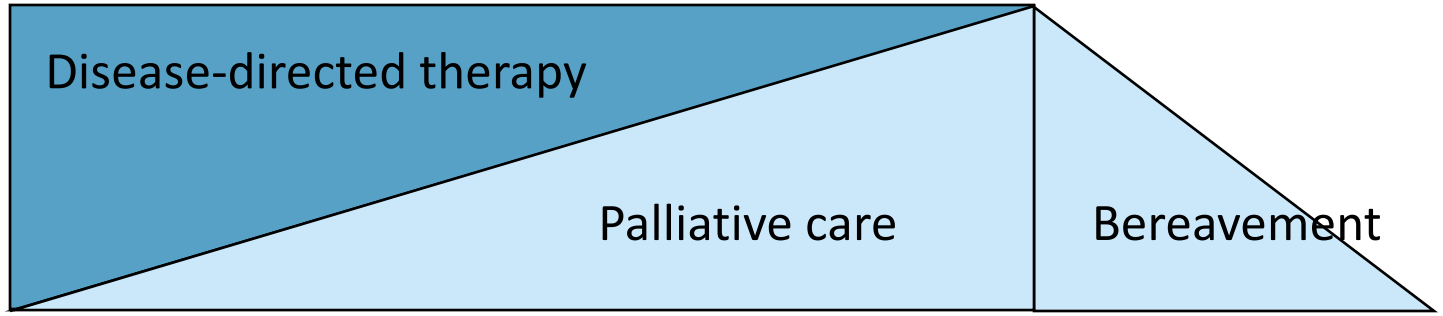


Hematological malignancies



Solid Tumours



Canadian Hospice Palliative Care Association, 2002

Symptoms and EOL care in HM vs. solid tumours

- **High symptom prevalence**
  - Similar to solid tumours: pain, dyspnea, nausea
  - More than solid tumours: fatigue, drowsiness, anorexia, delirium
- **Less advance directives and more aggressive care**
  - Increased ED, ICU, acute hospital admissions
  - Increased chemotherapy and targeted therapies at EOL
- **Less and later referral to palliative care and hospice**

Leblanc et al. Lancet Haematol. 2015; Odejide et al. JAMA IM 2016; Zimmermann et al. Leuk Res. 2013

Symptom	Overall prevalence (%)	Severity (%)[a]	Frequency (%)[b]
Psychological group			
Difficulty sleeping	55.2	44.0**	30.2**
Worrying	43.2	28.0	15.3
Difficulty concentrating	39.2	20.0	11.1
Feeling sad	35.6	22.4	8.5
Feeling nervous	30.8	20.8	9.8
Feeling irritable	20.0	10.8	5.5
Physical group			
Lack of energy*	79.2	57.2**	43.8**
Feeling drowsy*	56.4	37.6**	18.3
Dry mouth*	54.0	35.2	31.5**
Weight loss*	53.6	31.6	*NE*
Lack of appetite*	52.0	39.2**	31.9**
Change in taste of food*	51.2	37.2	*NE*
Pain*	49.2	40.8**	19.6**
Nausea*	44.8	29.6	14.0
Changes in skin	42.2	31.2	*NE*
Hair loss	39.6	33.2	*NE*
Sweats	38.0	25.6	12.3
Diarrhea	32.0	22.8	16.2
Mouth sores	31.6	25.2	*NE*

**** Items ranking in the top 5 of ratings for frequency, severity and distress, respectively.**

Barriers to palliative care involvement

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

461 patients with advanced cancer
Early pc - palliative care team (outpatient clinic, MD and nurse) – vs. standard oncology care

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

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

71 patients and caregivers in both trial arms

- qualitative methods (grounded theory)
- semi-structured interviews
  - asked about perceptions of pc
  - compared views of intervention and control group

Perceptions of palliative care

Theme	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**…, but I didn't really have any connection to what it was. I just had an idea that it was when people were dying (P034i)

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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**…, but I didn't really have any connection to what it was. I just had an idea that it was when people were dying (P034i)

Perceptions of palliative care

Theme	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)
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Public knowledge and attitudes concerning palliative care

- **Survey of a panel of the Canadian public, N = 1518**
- 45% had high **perceived knowledge** about PC ("know what PC is and could explain it to someone else")
- 34% had high **actual knowledge** (knew 5/8 components of WHO definition)
- Participants with high perceived knowledge were **less** likely to believe that palliative care offers hope to patients (and those with high actual knowledge **more** likely)

BMJ

Zimmermann C, *et al*. *BMJ Supportive & Palliative Care* 2021;**0**:1–11. doi:10.1136/bmjspcare-2021-003340

Attitude and practice-related barriers for EPC

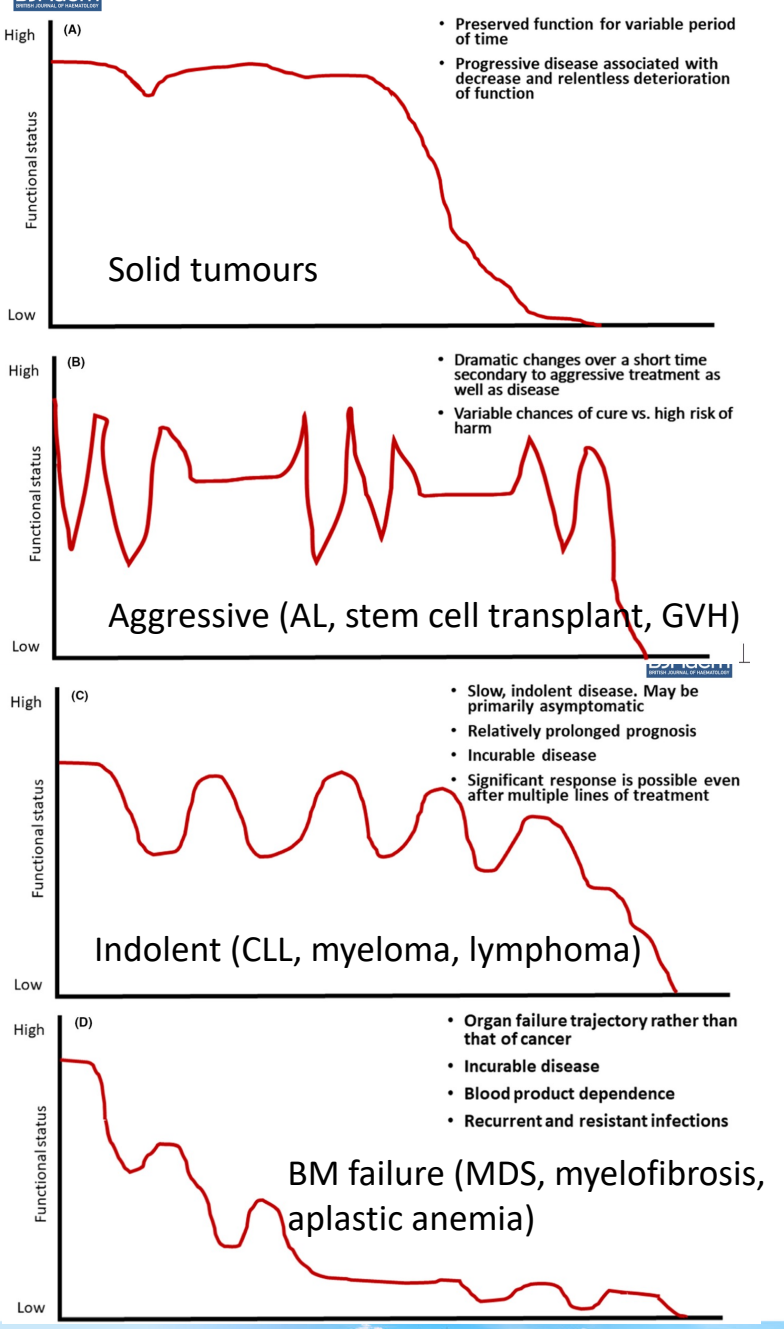
- **Haemato-oncologists vs. solid tumour oncologists**
  - Less likely to refer to PC, and more likely to refer later
  - More likely to believe PC = EOL care and less comfortable discussing dying
  - More likely to prescribe systemic therapy with moderate toxicity and no survival benefit to patients with prognosis < 1 month
- **Late referrals more likely if oncologists (both solid tumour and HM)…**
  - Have inadequate access to palliative care services
  - Have negative perceptions of palliative care - or believe their patients do
  - Have not completed a rotation in palliative care

Wentlandt et al. J Clin Oncol 2012; Hui et al. Ann Oncol 2015; Leblanc et al. J Oncol Pract 2015

Disease-related barriers: difficulties with prognostication in HM

- **Highly unpredictable disease course**
- Systematic review did not find effective prognostic indicators beyond immediately life-threatening events (e.g. multiorgan failure)
  - Cachexia, performance status, symptom burden not as strongly correlated with survival as in solid tumours
- Consensus among haematologists about potential signals for transition to EOL
  - Refractory disease; CNS involvement

Shaulov et al. Br J Haematol 2022; Button et al. BMC Cancer 2017; Odejide et al. J Oncol Pract 2014



Policy-related barriers for EPC in HM

- Hospice/PCU/home palliative care criteria may exclude many patients with HM due to use at the EOL of:
  - Broad spectrum antibiotics and antifungals
  - RBC transfusion
  - Platelet transfusion
  - Intravascular devices
  - Total parenteral nutrition
- Advocacy for policy change by American Society of Haematology
- Recent legislation to enable blood product transfusion in US hospice setting

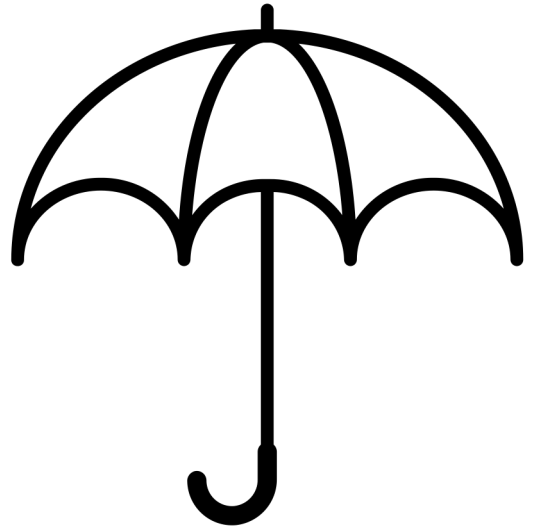
Shaulov et al. Br J Haematol 2022; Booker et al. Curr Oncol 2020; Cheng et al. Am J Hosp Palliat Care 2015

Viewpoint

March 17, 2022

Palliative Care Is the Umbrella, Not the Rain—A Metaphor to Guide Conversations in Advanced Cancer

Camilla Zimmermann, MD, PhD[1,2,3]; Jean Mathews, MD[1,2,4]

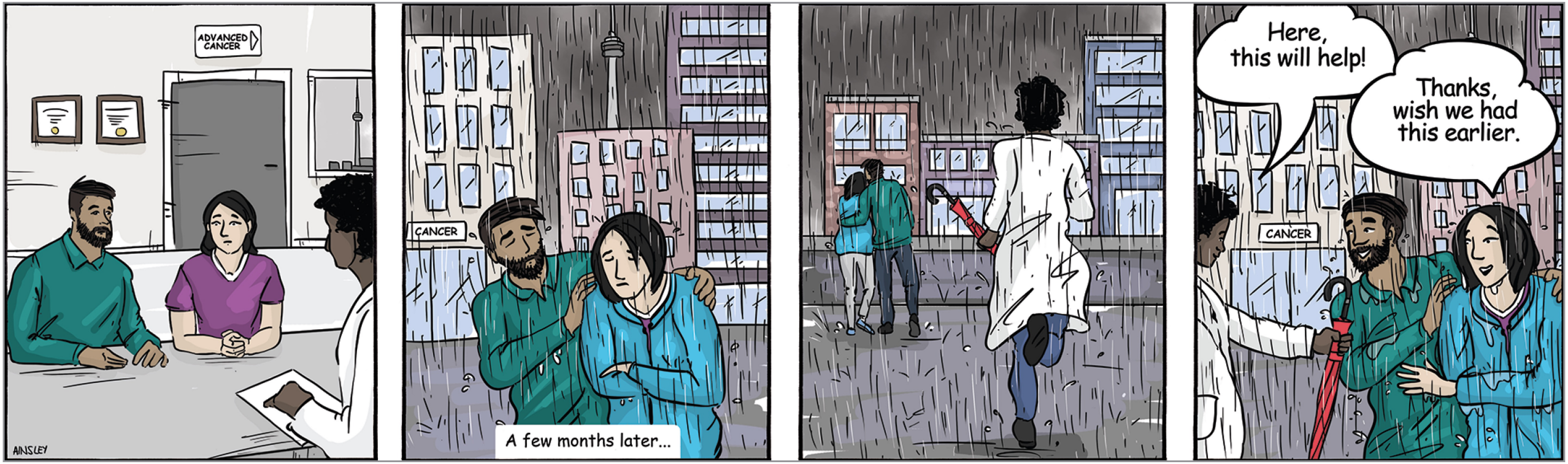


- **Palliative care is the umbrella, not the rain**
  - Rain is the symptoms and emotional distress of advanced cancer
- **Predicting the rain can be difficult**
  - Consult palliative care early “just in case”
- **Having an umbrella will not bring on the rain**
  - Avoiding the umbrella will result only in getting wet

JAMA Oncol. 2022;8(5):681-682

From: **Palliative Care Is the Umbrella, Not the Rain—A Metaphor to Guide Conversations in Advanced Cancer**

A Late palliative care referral

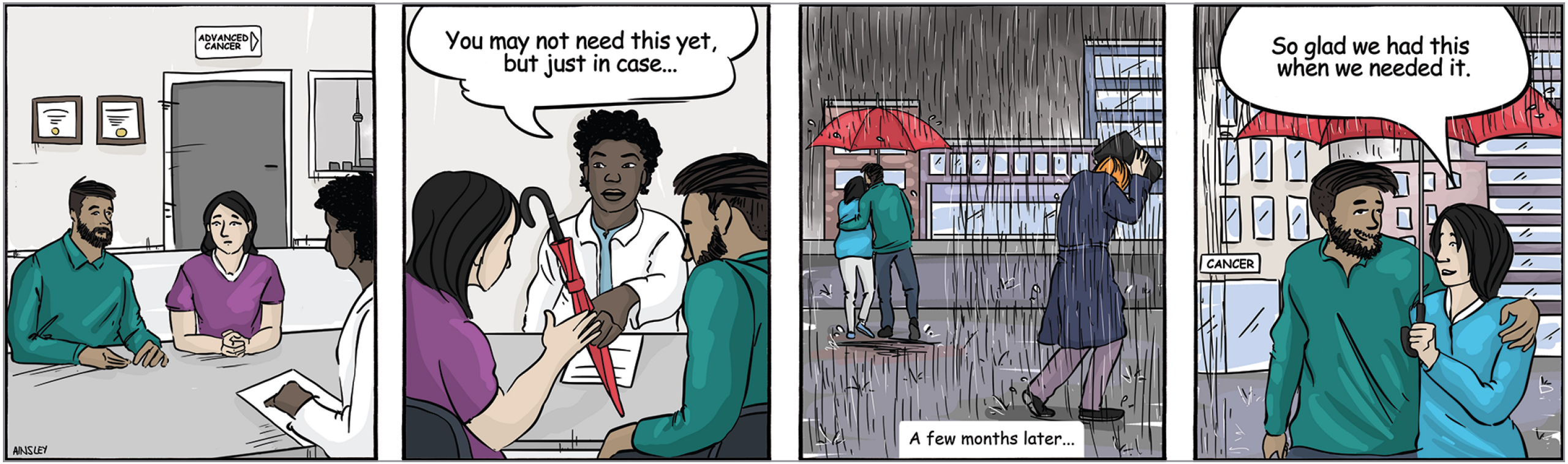


Zimmermann, Mathews. JAMA Oncol 2022

JAMA Network™

From: **Palliative Care Is the Umbrella, Not the Rain—A Metaphor to Guide Conversations in Advanced Cancer**

B Early palliative care referral



Zimmermann, Mathews. JAMA Oncol 2022

Conclusions

- There is **good evidence for the benefit of early palliative care** in solid tumours, and emerging evidence in haematologic malignancies, particularly for QOL and psychological symptoms

- Despite guidelines recommending early palliative care involvement, **referral is often late**, particularly in haematologic malignancies

- Although there are disease-related barriers for early palliative care involvement in haematologic malignancies (e.g. prognosticating, ability to provide blood products), **perceptions of palliative care and attitudes toward it** remain a key barrier that remains to be overcome

Grazie Mille!

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Clinical palliative care team

Patients and families participating in research

Harold and Shirley Lederman Chair in Palliative Care and Psychosocial Oncology, Princess Margaret Cancer Center/University Health Network/University of Toronto

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