

Dalle linee guida alla qualità di vita e alle cure palliative precoci e simultanee:

come la storia delle leucemie mieloidi acute sta cambiando



Roma, 2 febbraio 2024 – Starhotels Metropole

Le cure palliative precoci e simultanee in oncologia ed emato-oncologia

Elena Bandieri
Modena

Cicely Saunders (1918- 2005)
Hospice Movement



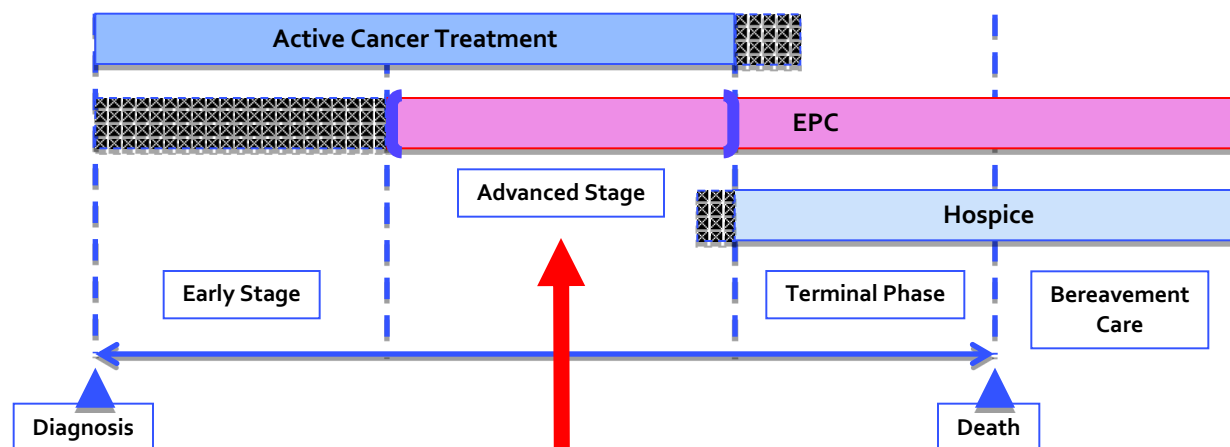
St. Christopher, 1967

Balfourt Mount in 1975,
Canada, creò il termine
«Palliative Care»



PASSATO:
CURE PALLIATIVE DI
FINE VITA
IMPORTANTI MA NON
SUFFICIENTI

Cure Palliative Precoci in Pazienti Oncologici ed Emato-Oncologici



PRESENTE:
CURE PALLIATIVE
PRECOCI (EPC)
DURANTE TUTTA LA
TRAIETTORIA DI
MALATTIA

Smith et al. J Clin Oncol 2012;30: 880–887 ,

Ferrell et al. J Clin Oncol 2017; 35: 96-112

Dalle linee guida alla qualità di vita e alle cure palliative precoci e simultanee:
come la storia delle leucemie mieloidi acute sta cambiando

Roma, 2 febbraio 2024
Starhotels Metropole



Early Palliative Care: Quali benefici evidence-based

1. Controllo dei **sintomi fisici** (in primis il **dolore**) e **psicologici** (ansia, depressione e disordini di stress post-traumatico)
2. Miglioramento di **QoL**
3. Promuovono il **coping adattativo** di una malattia inguaribile, costruendo una **relazione medico -paziente-caregivers**
4. Favoriscono la comprensione della **prognosi di malattia, supportano la discussione degli obiettivi EOL care e le scelte dell' astensione dalle terapie attive**



Benefici clinici in studi randomizzati e nella pratica clinica
in oncologia ed in ematologia

Differenze tra pazienti con neoplasie solide ed ematologiche

Criticità nella implementazione del modello EPC

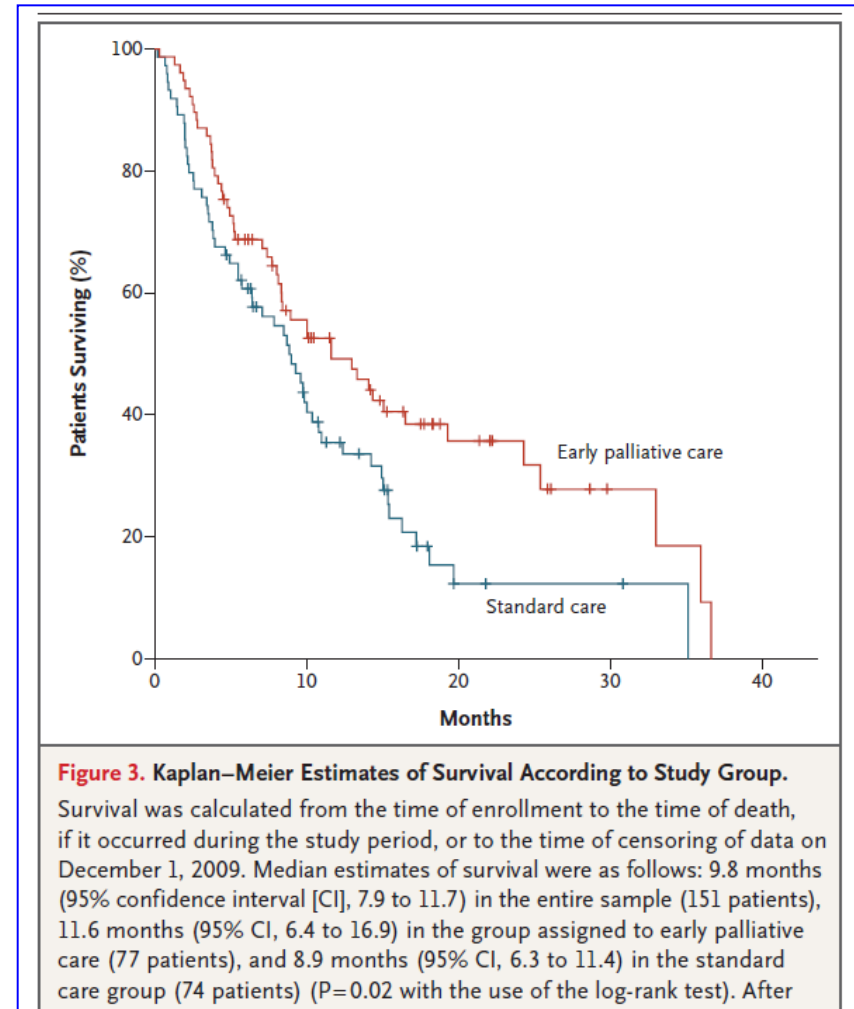
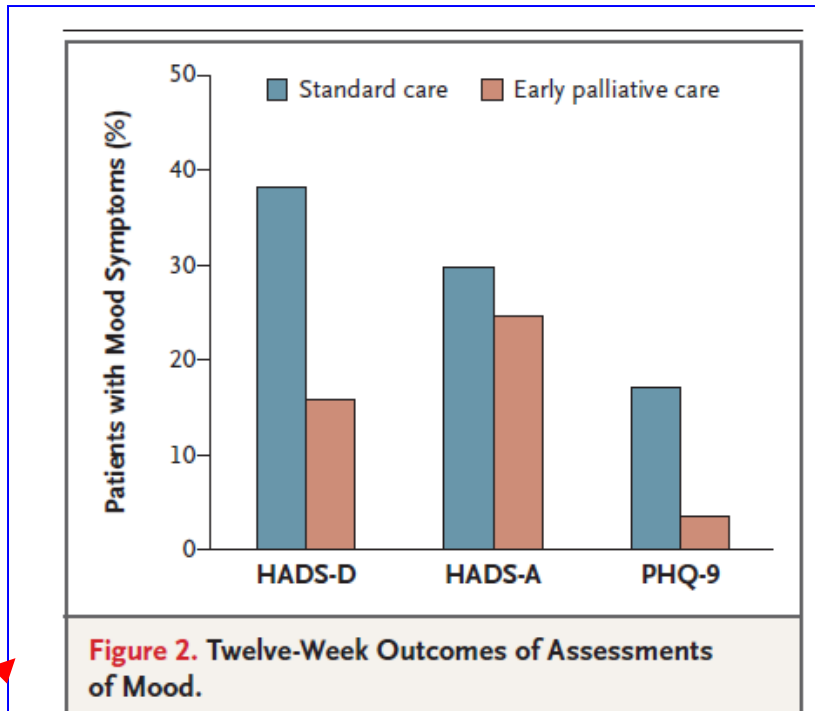
Obiettivi futuri di ricerca; Monitoraggio dei *PROs*, *Comunicazione medico-infermiere-paziente*, *Formazione*



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.

N ENGL J MED 363;8 NEJM.ORG AUGUST 19, 2010



Early Palliative Care: accanimento terapeutico nel fine vita

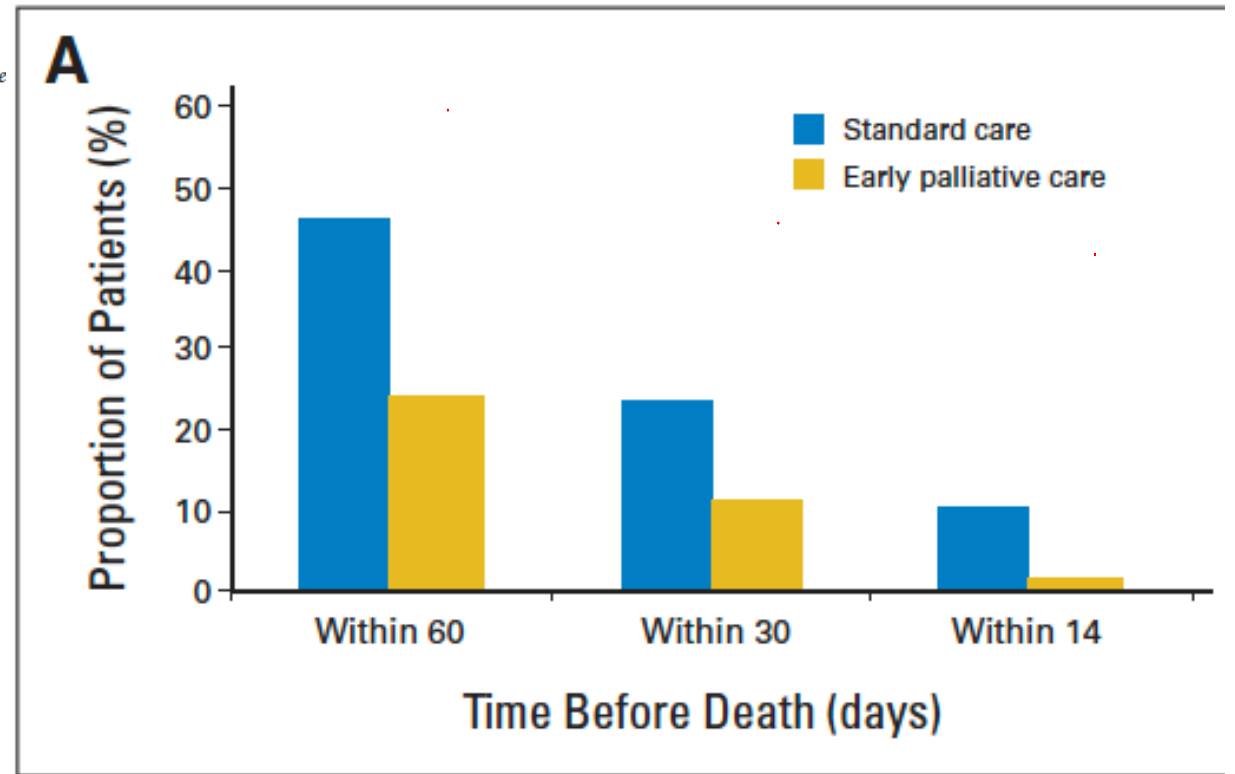
VOLUME 30 · NUMBER 4 · FEBRUARY 1 2012

JOURNAL OF CLINICAL ONCOLOGY

ORIGINAL REPORT

Effect of Early Palliative Care on Chemotherapy Use and End-of-Life Care in Patients With Metastatic Non–Small-Cell Lung Cancer

Joseph A. Greer, William F. Pirl, Vicki A. Jackson, Alona Muzikansky, Inga T. Lennes, Rebecca S. He Emily R. Gallagher, and Jennifer S. Temel



Early Versus Delayed Initiation of Concurrent Palliative Oncology Care: Patient Outcomes in the ENABLE III Randomized Controlled Trial

Marie A. Bakitas, Tor D. Tosteson, Zhigang Li, Kathleen D. Lyons, Jay G. Hull, Zhongze Li, J. Nicholas Dionne-Odom, Jennifer Frost, Konstantin H. Dragnev, Mark T. Hegel, Andres Azuero, and Tim A. Ahles

Entro 30-60 giorni

Ritardo di 3 mesi

Table 1. Baseline Demographic and Clinical Characteristics of Patient Participants

Characteristic	Early Group (n = 104)		Delayed Group (n = 103)		P*
	No.	%	No.	%	
Age, years					.68
Mean	64.03		64.6		
SD	10.28		9.59		
Male sex	56	53.85	53	51.46	.78
Diagnosis					.97
Lung	46	44.23	42	40.78	
GI tract	26	25	24	23.3	
Breast	10	9.62	13	12.62	
Other solid tumor	10	9.62	10	9.71	
Genitourinary tract	7	6.73	9	8.74	
Hematologic malignancy	5	4.81	5	4.85	
Disease status at enrollment					.24
New diagnosis	48	46.15	46	44.66	
Recurrence	29	27.88	20	19.42	
Progression	27	25.96	36	34.95	
Do not know	0	0.0	1	0.97	
Brain metastasis at enrollment	17	16.35	18	17.48	.71
Charlson score	6.3	1.62	6.21	1.86	.71
Karnofsky performance status	80.58	10.87	81.46	9.74	.54
Anticancer treatment at enrollment					
Chemotherapy	76	73.08	80	77.67	.52
Radiotherapy	20	19.23	20	19.42	1.00

Modello medico infermieristico



Early Palliative Care: OS

Il miglioramento del 15% della sopravvivenza ad un anno in pazienti oncologici,

che ricevono un intervento di cure palliative precoci entro 8 sett. (vs > 3 mesi) è in linea con il vantaggio in studio Temel, NEJM 2010 (11.6 v 8.9 months).

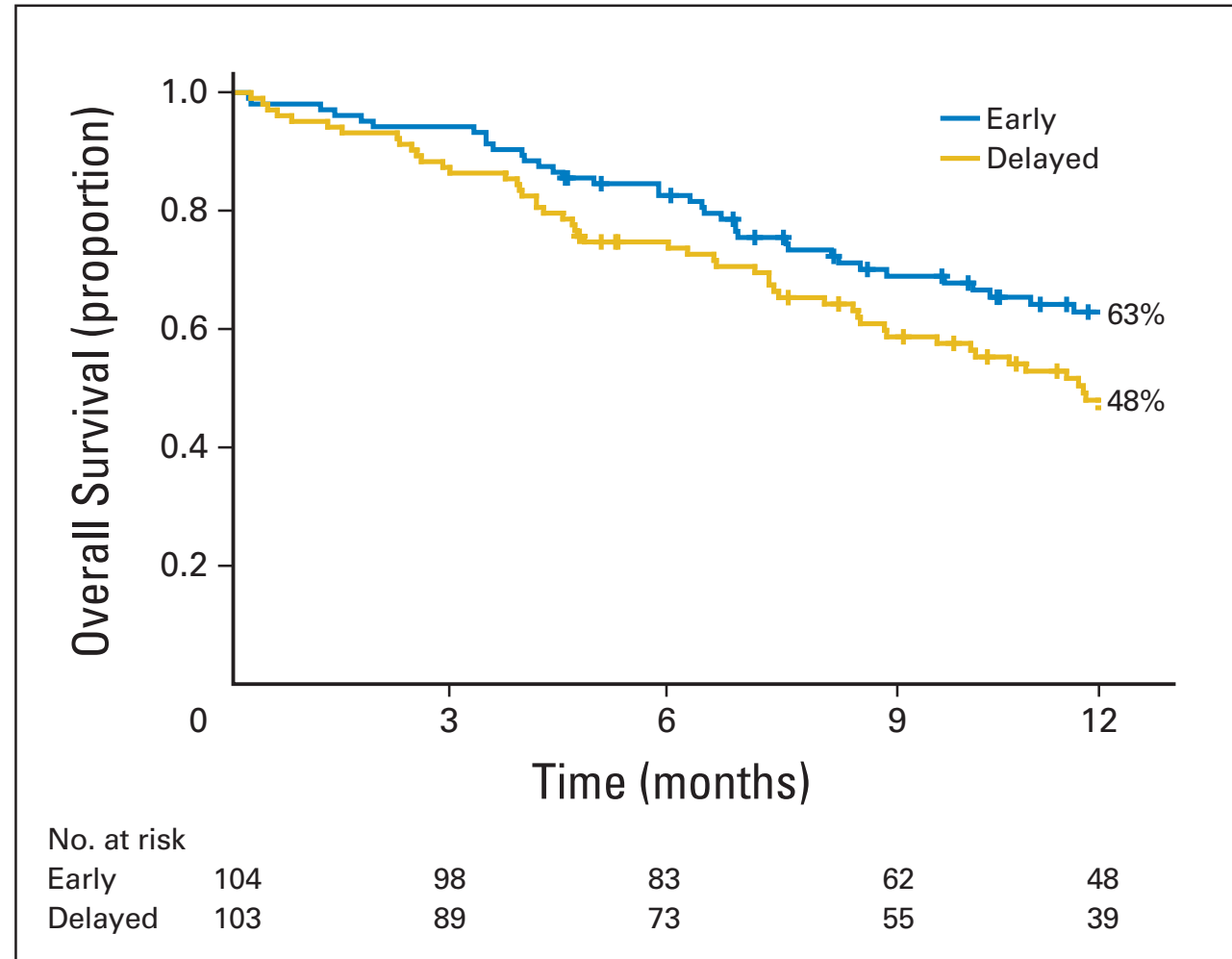


Fig 2. Kaplan-Meier estimates of 1-year survival by treatment group.



Early Palliative Care: i benefici per i caregivers

VOLUME 33 · NUMBER 13 · MAY 1 2015

JOURNAL OF CLINICAL ONCOLOGY

ORIGINAL REPORT

Benefits of Early Versus Delayed Palliative Care to Informal Family Caregivers of Patients With Advanced Cancer: Outcomes From the ENABLE III Randomized Controlled Trial

J. Nicholas Dionne-Odom, Andres Azuero, Kathleen D. Lyons, Jay G. Hull, Tor Tosteson, Zhigang Li, Zhongze Li, Jennifer Frost, Konstantin H. Dragnev, Imatullah Akyar, Mark T. Hegel, and Marie A. Bakitas

Early-group: I caregivers avevano significativamente minore depressione e *distress* psicologico a 3 mesi da intervento (riduzione del 6%)



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 OUTPATIENT	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	=	=	=

Courtesy of C. Zimmermann

Early palliative care for patients with solid tumours

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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	=	=	=

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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	=
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Survival	=	+	n/a	+	n/a	n/a	=	=	=

Courtesy of C. Zimmermann

Early palliative care for patients with solid tumours

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Depression	+	+	n/a	=	=	+	=	=	=
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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	=	=	=

Courtesy of C. Zimmermann

Benefici clinici in studi randomizzati e **nella pratica clinica**
in oncologia ed in ematologia

Differenze tra pazienti con neoplasie solide ed ematologiche

Criticità nella implementazione del modello EPC

Obiettivi futuri di ricerca; Monitoraggio dei *PROs*, *Comunicazione medico-infermiere-paziente*, *Formazione*



EPC E IL CONTROLLO DEL DOLORE

Annals of Oncology Advance Access published May 10, 2012

original article

Annals of Oncology
doi:10.1093/annonc/mds103

Impact of early access to a palliative/supportive care intervention on pain management in patients with cancer

E. Bandieri^{1†}, D. Sichetti^{2†}, M. Romero^{2†}, C. Fanizza², M. Belfiglio², L. Buonaccorso¹, F. Artioli¹, F. Campione³, G. Tognoni² & M. Luppi^{4*}

[†]Palliative Care Unit Azienda Unitaria Sanitaria Locale (USL), Modena; ²Department of Clinical Pharmacology and Epidemiology, Consorzio Mario Negri Sud, Santa Maria Imbaro, Chieti; ³Institute of Tanatologia, Clinica della crisi, I.A.T.S., University of Bologna, Bologna; ⁴Department of Oncology, Hematology and Respiratory Diseases, Azienda Ospedaliera Universitaria, Policlinico, Modena, Italy

Le EPC = fattore indipendente associato alla riduzione del dolore severo da cancro, del 31%.

Studio multicentrico, *cross-sectional* in 32 Ospedali Italiani **1.450** pazienti, con dolore da cancro: **602** con accesso a terapie standard e **848** con accesso a EPC

Table 5. Factors associated with severe pain prevalence

Variables	Univariate		Multivariate	
	RR (95 % CI)	P value	RR (95 % CI)	P value
Care model				
SC	1		1	
ePSC	0.69 (0.48–0.99)	0.037	0.69 (0.48–0.99)	0.045
Wards				
Oncology	1.00 (0.75–1.35)	0.98	1.02 (0.76–1.36)	0.91
Non-oncology	1		1	
Metastatic disease				
No	1.12 (0.89–1.41)	0.35	1.16 (0.92–1.46)	0.22
Yes	1		1	
Gender				
Males	0.75 (0.62–0.90)	0.002	0.76 (0.63–0.91)	0.003
Females	1		1	
Age	0.99 (0.99–1.00)	0.016	1.00 (0.99–1.00)	0.25
Analgesic therapy				
Non-opioids	1.00		1	
Weak opioids	1.19 (0.74–1.92)	0.47	1.12 (0.70–1.79)	0.64
Strong opioids	1.38 (0.88–2.17)	0.16	1.00 (0.84–2.05)	0.23

CI, confidence interval; ePSC, early palliative/supportive care; RR, relative risk; SC, standard care.



Early versus delayed palliative/ supportive care in advanced cancer: an observational study

2014-2017

Elena Bandieri,¹ Federico Banchelli,² Fabrizio Artioli,¹ Claudia Mucciarini,¹ Giorgia Razzini,¹ Massimiliano Cruciani,¹ Leonardo Potenza,³ Roberto D'Amico,² Fabio Efficace,⁴ Eduardo Bruera,⁵ Mario Luppi³

BMJ

Bandieri E, et al. *BMJ Supportive & Palliative Care* 2019;0:1-10. doi:10.1136/bmjspcare-2019-001794

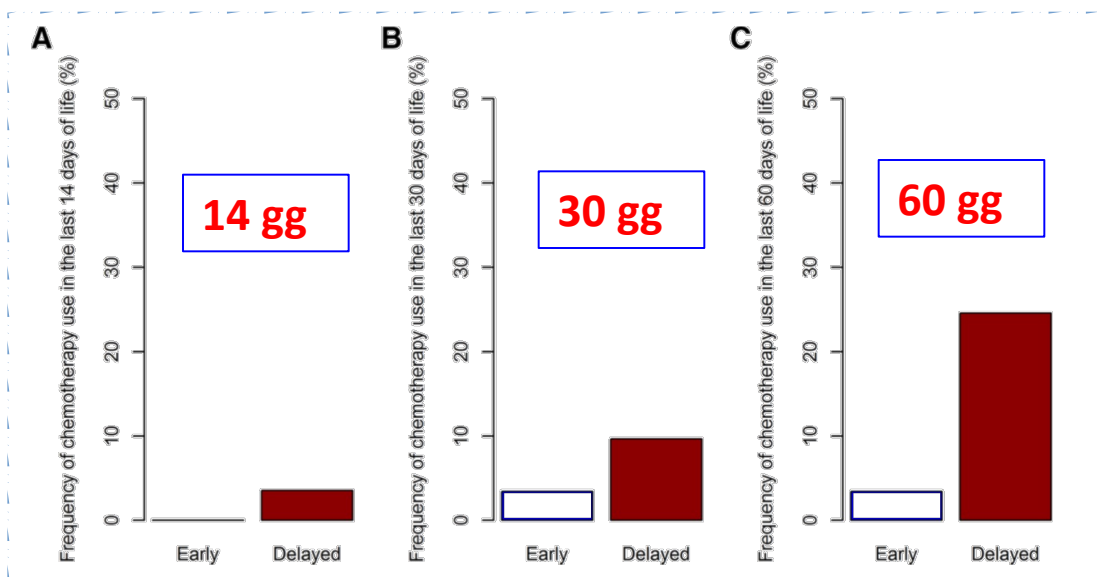
EPC: dolore, accanimento terapeutico e OS

Table 5 NRS at baseline and over time in the whole sample

	NRS (0-10)*		Comparison with baseline
	Median	IQR	P value
Time 0 (baseline)	7	6-8	NA
Time 1 (after 1 week)	1	0-2	0.000
Time 2 (after 4 weeks)	1	1-2	0.000
Time 3 (after 12 weeks)	1	0-1	0.000

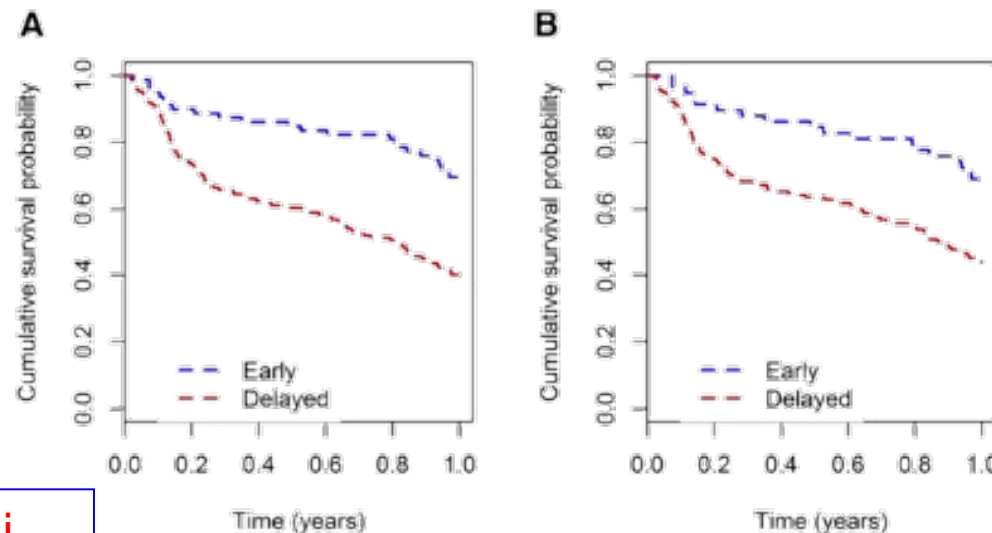
*Data available only for 178 patients.

NA, not applicable; NRS, Numerical Rating Scale.



Early 60 gg dopo la diagnosi

Delayed 90 gg dopo la diagnosi



Benefici clinici in studi randomizzati e nella pratica clinica
in oncologia ed **in ematologia**

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Criticità nella implementazione del modello EPC

Obiettivi futuri di ricerca; Monitoraggio dei *PROs*, *Comunicazione medico-infermiere-paziente*, *Formazione*



Effect of Inpatient Palliative Care on Quality of Life 2 Weeks After Hematopoietic Stem Cell Transplantation: A Randomized Clinical Trial

Areej El-Jawahri, MD; Thomas LeBlanc, MD; Harry VanDusen, BS; Lara Traeger, PhD; Joseph A. Greer, PhD; William F. Pirl, MD; Vicki A. Jackson, MD; Jason Telles, NP; Alison Rhodes, NP; Thomas R. Spitzer, MD; Steven McAfee, MD; Yi-Bin A. Chen, MD; Stephanie S. Lee, MD, MPH; Jennifer S. Temel, MD

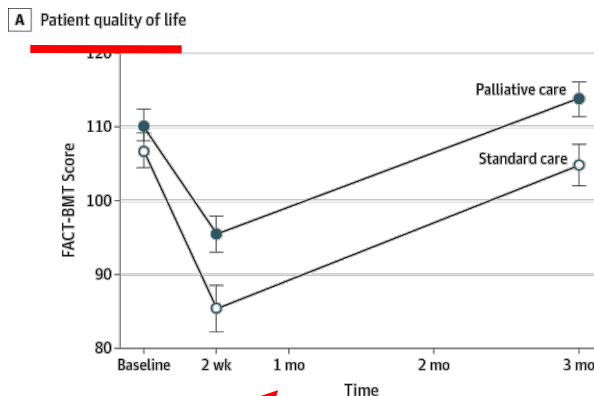
JAMA. 2016;316(20):2094-2103. doi:10.1001/jama.2016.16786

160 pazienti sottoposti a trapianto di cellule staminali emopoietiche randomizzati a ricevere EPC vs esclusivamente il trapianto.

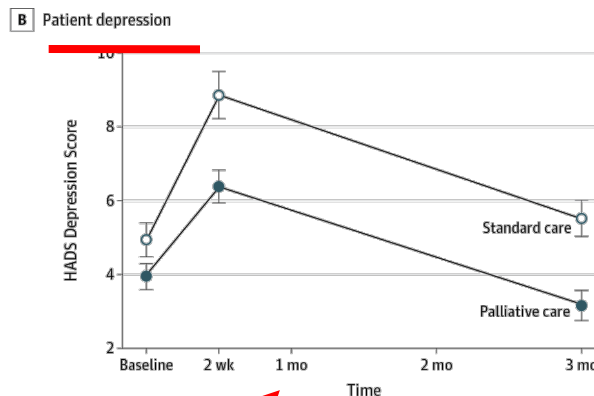
Intervento palliativo: medico o infermiere, due volte alla settimana, durante il ricovero

Migliore QoL, riduzione di ansia e depressione dei sintomi invalidanti.

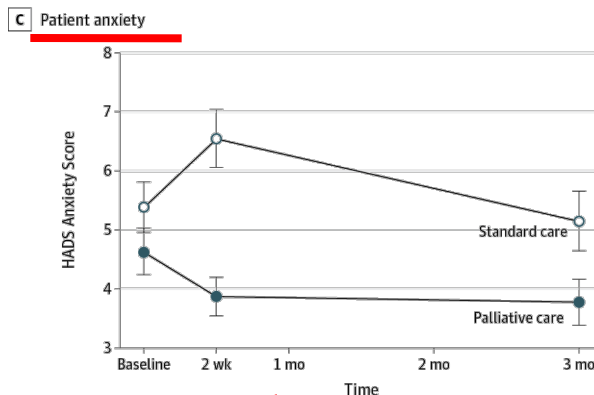
Caregivers depressione minore



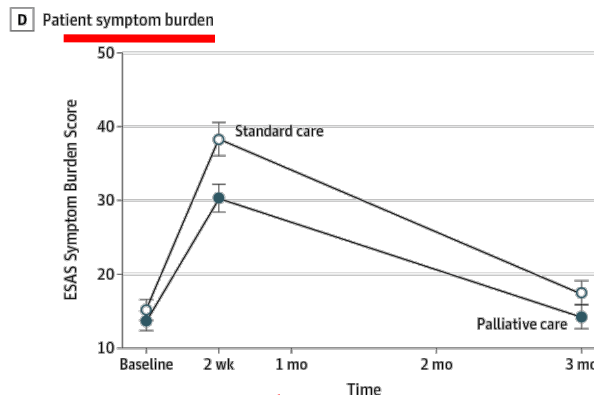
No. of patients	81	80	75
Palliative care	81	80	75
Standard care	79	77	74



No. of patients	81	80	74
Palliative care	81	80	74
Standard care	79	77	74



No. of patients	81	80	74
Palliative care	81	80	74
Standard care	79	77	74



No. of patients	77	75	69
Palliative care	77	75	69
Standard care	79	77	71

Transplant type, No. (%)		
Autologous HCT	39 (49.4)	41 (50.6)
Myeloablative allogeneic HCT	14 (17.7)	16 (19.8)
Reduced-intensity allogeneic HCT	26 (32.9)	24 (29.6)
Donor type (allogeneic), No. (%)		
Matched related donor	11 (27.5)	11 (27.5)
Matched unrelated donor	23 (57.5)	22 (55)
Haploidentical donor	4 (10.0)	7 (17.5)
Cord	2 (5.0)	0
HCT hospital length of stay, mean (SD), d	21.7 (5.4)	21.9 (11.2)
FACT-BMT score, mean (SD) ^a	107.3 (20.7)	110.3 (19.1)
FACT Fatigue score, mean (SD) ^b	36.9 (10.8)	38.1 (10.3)
PHQ-9 score, mean (SD) ^c	5.4 (4.7)	4.8 (4.4)
HADS Depression score, mean (SD) ^d	4.9 (4.1)	4.0 (3.2)
HADS Anxiety score, mean (SD) ^d	5.4 (3.8)	4.6 (3.6)



Effect of Inpatient Palliative Care During Hematopoietic Stem-Cell Transplant on Psychological Distress 6 Months After Transplant: Results of a Randomized Clinical Trial

Areej El-Jawahri, Lara Traeger, Joseph A. Greer, Harry VanDusen, Sarah R. Fishman, Thomas W. LeBlanc, William F. Pirl, Vicki A. Jackson, Jason Telles, Alison Rhodes, Zhigang Li, Thomas R. Spitzer, Steven McAfee, Yi-Bin A. Chen, and Jennifer S. Temel

L'effetto dell'intervento era mantenuto anche a 6 mesi con miglioramento della depressione e dell'ansia e riduzione del disturbo post-traumatico da stress.

Table 2. Effect of the Inpatient Palliative Care Intervention on Patient-Reported Outcomes at 6 Months Post-Transplant

Assessment	Adjusted Mean Score*	95% CI	Adjusted Mean Difference Between Groups	95% CI	P
HADS-D (n = 141)					
Control	4.66	3.93 to 5.38	-1.21	-2.26 to -0.16	.024
Intervention	3.45	2.70 to 4.19			
HADS-A (n = 141)					
Control	4.74	3.99 to 5.49	-0.61	-1.69 to 0.47	.267
Intervention	4.13	3.36 to 4.90			
PHQ-9 depression symptoms (n = 142)					
Control	5.58	4.57 to 6.60	-1.63	-3.08 to -0.19	.027
Intervention	3.95	2.93 to 4.98			
PCL (n = 134)					
Control	26.18	23.96 to 28.39	-4.02	-7.18 to -0.86	.013
Intervention	22.15	19.91 to 24.40			
FACT-BMT (n = 141)					
Control	109.39	105.38 to 113.41	2.72	-2.96 to 8.39	.346
Intervention	112.11	108.12 to 116.10			
FACT fatigue (n = 143)					
Control	37.38	34.94 to 39.83	0.10	-3.38 to 3.58	.957
Intervention	37.48	35.01 to 39.94			

NOTE. Boldface indicates significant $P < .05$.
 Abbreviations: FACT-BMT, Functional Assessment of Cancer Therapy-Bone Marrow Transplant; HADS-A, Hospital Anxiety and Depression Scale anxiety subscale; HADS-D, Hospital Anxiety and Depression Scale depression subscale; PCL, Post-Traumatic Stress Disorder Checklist; PHQ-9, Patient Hospital Questionnaire 9.
 *The adjusted mean score is the predicted outcome score at the average baseline value for all participants.



Effectiveness of Integrated Palliative and Oncology Care for Patients With Acute Myeloid Leukemia

A Randomized Clinical Trial

Areej El-Jawahri, MD; Thomas W. LeBlanc, MD; Alison Kavanaugh, NP; Jason A. Webb, MD; Vicki A. Jackson, MD; Toby C. Campbell, MD; Nina O'Connor, MD; Selina M. Luger, MD; Elin Gafford, MD; Jillian Gustin, MD; Bhavana Bhatnagar, DO; Alison R. Walker, MD; Amir T. Fathi, MD; Andrew M. Brunner, MD; Gabriela S. Hobbs, MD; Showly Nicholson, BS; Debra Davis, RN, BSN; Hilena Addis, BS; Dagny Vaughn, BA; Nora Horick, MS; Joseph A Greer, PhD; Jennifer S. Temel, MD

Measure (Scale)	Sample size	Group assignment	Adjusted Mean Score (95% CI)	Standardized Mean Difference	P value
Quality of life (FACT-Leukemia)	139	Usual care	107.59 (101.45-113.74)	0.30	.04
		Integrated palliative and oncology care	116.45 (110.69-122.21)		
Anxiety symptoms (HADS)	147	Usual care	5.94 (5.10-6.79)	0.31	.02
		Integrated palliative and oncology care	4.53 (3.74-5.33)		
Depression symptoms (HADS)	147	Usual care	7.20 (6.26-8.14)	0.34	.02
		Integrated palliative and oncology care	5.68 (4.80-6.56)		
Depression syndrome (PHQ-9)	144	Usual care	8.00 (6.83-9.17)	0.31	.04
		Integrated palliative and oncology care	6.34 (5.23-7.44)		
Symptom burden (ESAS)	146	Usual care	32.82 (28.58-37.06)	0.23	
		Integrated palliative and oncology care			

Paz >= 18 anni, *high-risk AML*
 Sottoposti a chemioterapia intensiva :

- 1) *AML* di nuova diagnosi, >= 60 anni;
- 2) *AML* primariamente refrattaria e recidivata



	Usual care N/Tot (%)	Integrated palliative and oncology care N/Tot (%)	P value
Deceduti	44/73 (60)	43/84 (51)	
Discussion about EOL preferences	12/30 (40)	21/28 (75)	.01

EPC NEW Standard OF CARE for AML

Intervento palliativo da **medico-infermiere**, due volte alla settimana, durante il ricovero.
 Valutazione indicatori esiti a **2 settimane**



Benefici clinici in studi randomizzati e nella pratica clinica
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Differenze tra pazienti con neoplasie solide ed ematologiche

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Obiettivi futuri di ricerca; Monitoraggio dei *PROs*, *Comunicazione medico-infermiere-paziente*, *Formazione*



IL DOLORE in EMATOLOGIA

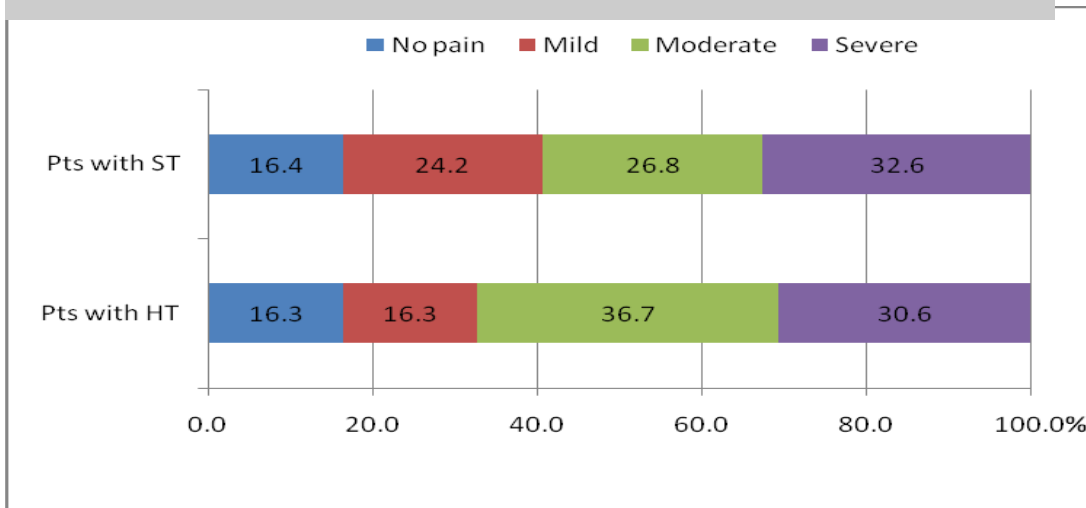
Is pain in patients with haematological malignancies under-recognised? The results from Italian ECAD-O survey

Bandieri et al.,

Leukemia Research 34 (2010) e334–e335

Solid Tumors 59.4% moderate severe

Hematologic Tumors 67.3% moderate-severe



Supportive Care in Cancer (2019) 27:2789–2797
<https://doi.org/10.1007/s00520-018-4583-5>

ORIGINAL ARTICLE



Pain in patients with newly diagnosed or relapsed acute leukemia

Adir Shaulov^{1,2} · Gary Rodin^{1,3} · Gordana Popovic¹ · Valerie B. Caraiscos^{1,4} · Lisa W. Le⁵ · Anne Rydall¹ · Aaron D. Schimmer^{6,7} · Camilla Zimmermann^{1,3,8}

Table 2 Pain frequency, severity and distress

	Frequency		Severity		Distress	
	n	%	n	%	n	%
0	161	50.8	161	51.3	169	53.8
1	31	9.8	26	8.3	37	11.8
2	59	18.6	72	22.9	37	11.8
3	42	13.3	42	13.4	36	11.5
4	24	7.6	13	4.1	35	11.2

For frequency, 0 = did not have, 1 = rarely, 2 = occasionally, 3 = frequently, 4 = almost constantly. For severity, 0 = did not have, 1 = slight, 2 = moderate, 3 = severe, 4 = very severe. For distress, 0 = not at all or did not have, 1 = a little bit, 2 = somewhat, 3 = quite a bit, 4 = very much

Missing data: frequency, 1 patient; severity, 4 patients; distress, 4 patients

Dolore nel 49,9% dei pazienti con leucemia acuta; dolore severo nel 35.3%.



EPC: IL CONTROLLO DEL DOLORE

Early palliative/supportive care in acute myeloid leukaemia allows low aggression end-of-life interventions: observational outpatient study


Leonardo Potenza ¹, Miki Scaravaglio,¹ Daniela Fortuna,² Davide Giusti,¹ Elisabetta Colaci,¹ Valeria Pioli,¹ Monica Morselli,¹ Fabio Forghieri,¹ Francesca Bettelli,¹ Andrea Messerotti,¹ Hillary Catellani,¹ Andrea Gilioli,¹ Roberto Marasca,¹ Eleonora Borelli ³, Sarah Bigi,⁴ Giuseppe Longo,⁵ Federico Banchelli,⁶ Roberto D'Amico,⁶ Anthony L Back,⁷ Fabio Efficace ⁸, Eduardo Bruera ⁹, Mario Luppi ¹, Elena Bandieri¹⁰

Table 1 Characteristics of patients with AML enrolled in the study

	ePSC	Late PC
Total, n	131	84
Age, mean±SD (range)	65.5±13.3 (21.0–91.5)	55.8±16.8 (17.1–91.9)
Male, n (%)	75 (57.3)	43 (51)
AML initial therapy, n (%)		
Intensive	80 (61.1)	67 (80)
Non-intensive	31 (23.7)	7 (8)
Supportive care alone	20 (15.3)	10 (12)
Weeks to PC team referral, median (range)		NA
Whole population	5 (0–20.7)	
Delayed referral patients (n=13, 10%)	12 (9.3–20.7)	

AML, acute myeloid leukaemia; ePSC, early palliative supportive care; late PC, late referral to palliative care; NA, not applicable; SD, standard deviation.

BMJ

Potenza L, et al. *BMJ Supportive & Palliative Care* 2021;0:1–8. doi:10.1136/bmjspcare-2021-002898

Table 4 Pain assessment over time in patients with acute myeloid leukaemia receiving early palliative supportive care intervention

	NRS (0–10)		
	Median	95% CI	P value
Time 0 (baseline)	4	4 to 6	NA
Time 2 (after 1 week)	0	0 to 3	<0.01
Time 3 (after 4 weeks)	0	0 to 1	<0.01
Time 4 (after 12 weeks)	0	0 to 2	<0.01

NA, not applicable; NRS, Numerical Rating Scale.

2014-2019-Modena



Table 3 Measures of quality indicators for palliative care in patients with acute myeloid leukaemia receiving ePSC intervention or late referral PC

	ePSC, all		Late PC, all		RD, % (95% CI)	P value	ePSC, deceased		Late PC, deceased		RD, % (95% CI)	P value
	n/n	%	n/n	%			n/n	%	n/n	%		
Psychological support*, n (%)	72/131	55	41/84	49	61.5 (–7.5 to 19.8)	0.3781	39/75	52	22/40	55	–3 (–22.1 to 16.1)	0.7588
Assessing and managing pain*, n (%)	131/131	100	39/84	46	53.6 (43 to 64.2)	<0.00001	75/75	100	18/40	45	55 (39.5 to 70.4)	<0.00001
Discussion of GOC/prognosis*, n (%)	94/131	71.8	36/84	43	28.9 (15.8 to 42)	<0.00001	70/75	93.3	16/40	40	53.3 (37.1 to 69.5)	<0.00001
Promotion of ACP*, n (%)	75/131	57.3	2/84	2.3	54.9 (45.8 to 64)	<0.00001	64/75	85.3	2/40	5	80.3 (69.8 to 90.8)	<0.0001
Discussion of resuscitation preference*, n (%)	16/131	12.2	2/84	2.3	9.83 (3.3 to 16.3)	0.01111	15/75	20	2/40	5	15 (3.7 to 26.3)	0.0309
Home-care service utilisation*, n (%)	57/131	43.5	12/84	14.2	29.2 (17.9 to 40.5)	<0.00001	48/75	64	12/40	30	34 (16.1 to 51.9)	0.0005
Median duration of home care, days (range)	63.5 (3.0–3273.0)		53.0 (1–96)				57.0 (3.0–394.0)		53.0 (1–96)			
Median time from GOC to death, days (range)	NA		NA				106 (4.0–585.0)		149.5 (11–1714)			
Median time from ACP to death, days (range)	NA		NA				25 (4.0–401.0)		5.5 (4–7)			

*Indicators of quality for palliative care.³⁰

ACP, advance care planning; ePSC, early palliative supportive care; GOC, goals of care; late PC, late referral to palliative care; NA, not applicable; RD, risk difference.



EVIDENZE SCIENTIFICHE E RACCOMANDAZIONI CLINICHE

Early palliative/supportive care in acute myeloid leukaemia allows low aggression end-of-life interventions: observational outpatient study

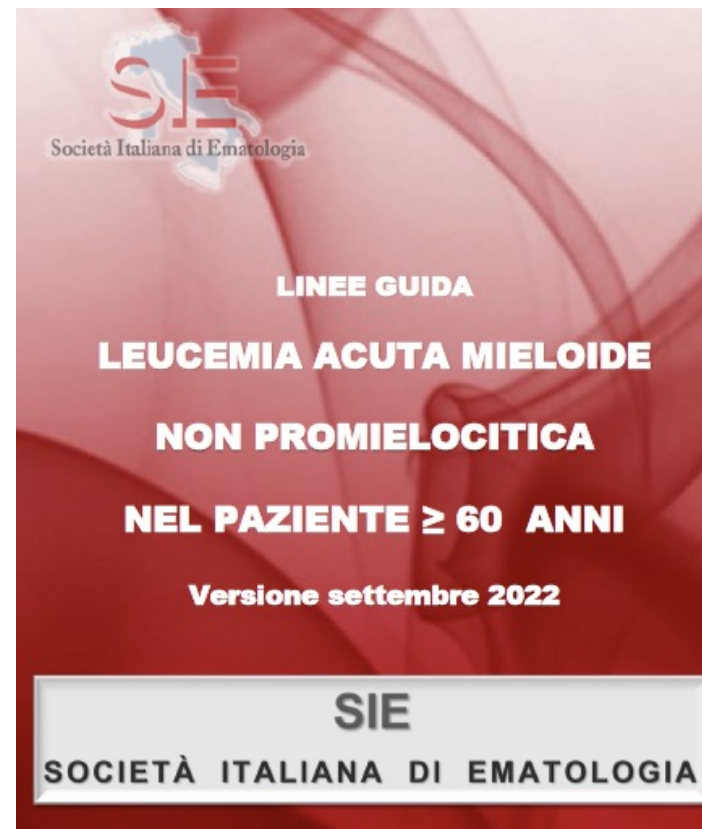
Leonardo Potenza ¹, Miki Scaravaglio,¹ Daniela Fortuna,² Davide Giusti,¹ Elisabetta Colaci,¹ Valeria Pioli,¹ Monica Morselli,¹ Fabio Forghieri,¹ Francesca Bettelli,¹ Andrea Messerotti,¹ Hillary Catellani,¹ Andrea Gilioli,¹ Roberto Marasca,¹ Eleonora Borelli ³, Sarah Bigi,⁴ Giuseppe Longo,⁵ Federico Banchelli,⁶ Roberto D'Amico,⁶ Anthony L Back,⁷ Fabio Efficace ⁸, Eduardo Bruera ⁹, Mario Luppi ¹, Elena Bandieri¹⁰

BMJ

Potenza L, et al. *BMJ Supportive & Palliative Care* 2021;0:1–8. doi:10.1136/bmjspcare-2021-002898

NUOVI MODELLI DI CURE PALLIATIVE PRECOCI SIA *INPATIENT* CHE *OUTPATIENT*

5. Il panel raccomanda, laddove fattibile, il precoce coinvolgimento del team di cure palliative e l'eventuale servizio di Assistenza Psicologica (istituzionale o supportato dalle Organizzazioni di Volontariato) nell'ottica di promuovere un simultaneo intervento dell'ematologo e del medico palliativista.



EPC: NON SOLO IN LMA

Short report

Early palliative care versus usual haematological care in multiple myeloma: retrospective cohort study

Davide Giusti,¹ Elisabetta Colaci,¹ Valeria Pioli,¹ Federico Banchelli,² Monica Maccaferri,¹ Giovanna Leonardi,¹ Roberto Marasca,¹ Monica Morselli,¹ Fabio Forghieri,¹ Francesca Bettelli,¹ Angela Cuoghi,¹ Paola Bresciani,¹ Andrea Messerotti,¹ Andrea Gilioli,¹ Anna Candoni,¹ Luca Cassanelli,¹ Elena Sbadili,¹ Ilaria Bassoli,³ Giuseppe Longo,⁴ Fabio Gilioli,⁵ Eleonora Borelli ,¹ Sarah Bigi,⁶ Roberto D'Amico,² Carlo Adolfo Porro,^{7,8} Oreofe Odejide,⁹ Camilla Zimmermann ,^{10,11} Fabio Efficace ,¹² Eduardo Bruera ,¹³ Mario Luppi ,¹ Elena Bandieri,¹⁴ Leonardo Potenza ¹

Table 1 Quality indicators for palliative care in patients with multiple myeloma receiving EPC or UHC

Indicators	EPC N=55 (%)	UHC N=231 (%)	Measure	Adjusted (95%CI)	P value
Psychological Support	64.4	28.6	OR	4.64 (2.41 to 8.43)	<0.0001
Assessing and managing pain	100	68.4	OR	nc	nc
Discussion of GOC	74.6	4.3	HR	21.44 (9.75 to 47.16)	<0.0001
Promotion of ACP	13.6	0.0	HR	nc	nc
Home care service utilisation	30.5	22.5	HR	1.1 (0.84 to 2.71)	0.1638

The analysis was adjusted for the following variables in the regression models: age (years), sex (male, female), stage (I, II, III), MMFS = Multiple Myeloma Frailty Score (fit, unfit, frail), intensity of first-line therapy (transplant, no transplant).
ACP, advanced care planning; EPC, early palliative care patients; GOC, goals of care; n, number; nc, no calculable; UHC, usual haematological care.

2

Giusti D, et al. *BMJ Supportive & Palliative Care* 2023;0:1–5. doi:10.1136/spcare-2023-004524

WHAT THIS STUDY ADDS

⇒ Patients with multiple myeloma (MM) receiving EPC, when compared with those undergoing usual haematological care, have better pain control, with longer use of strong opioids; higher rates of symptom management; more frequent goals of care discussions; earlier access to home care services and a trend towards higher quality of end-of-life care.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ This study supports the value of integrating EPC into MM routine practice and may also lay the groundwork for future prospective comparative studies either in this setting or in patients with other HM.



Benefici clinici in studi randomizzati e nella pratica clinica
in oncologia ed in ematologia

Differenze tra pazienti con neoplasie solide ed ematologiche

Criticità nella implementazione del modello EPC

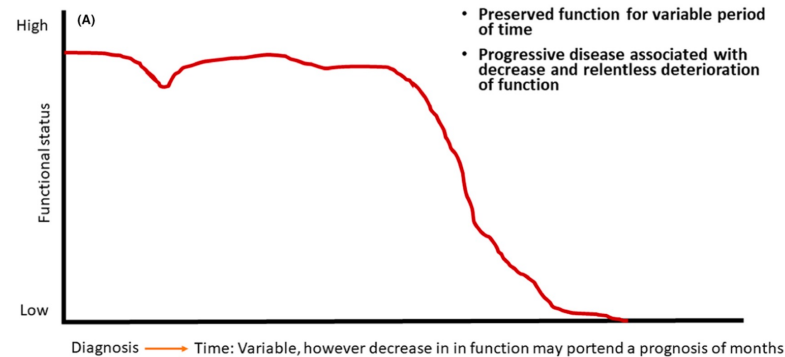
Obiettivi futuri di ricerca; Monitoraggio dei *PROs*, *Comunicazione medico-infermiere-paziente*, *Formazione*



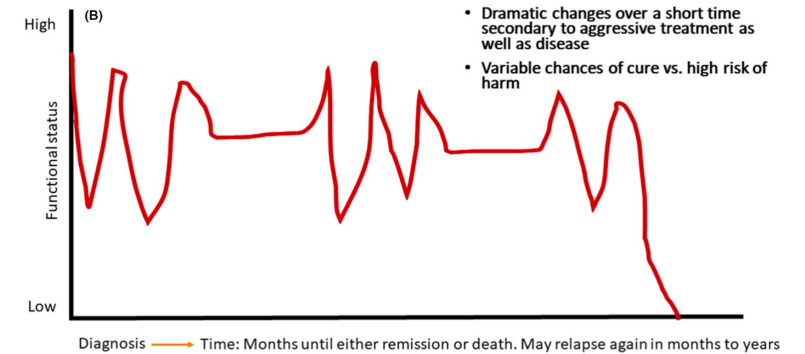
I pazienti ematologici presentano imprevedibili e peculiari traiettorie di malattia con la possibilità di cura e guarigione anche in caso di recidiva e di refrattarietà.

Proprio queste peculiarità influiscono sulla difficoltà di prognosi e del timing di Interventi di Cure Palliative Precoci

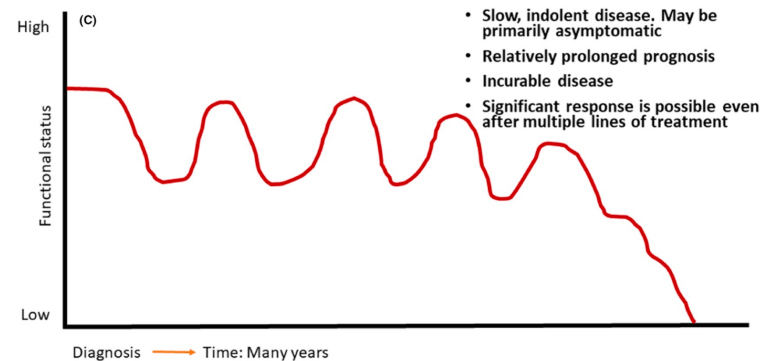
Cancri Solidi Metastatici



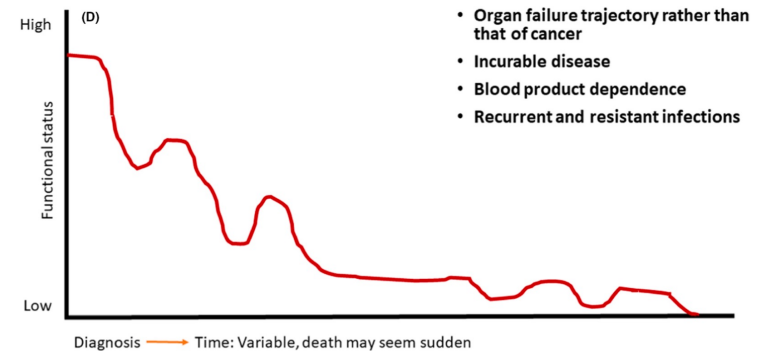
LMA, LLA, Linfomi non-H, B Alto Grado



MM, LLC



SMD, MFI, AA, fine vita



Benefici clinici in studi randomizzati e nella pratica clinica
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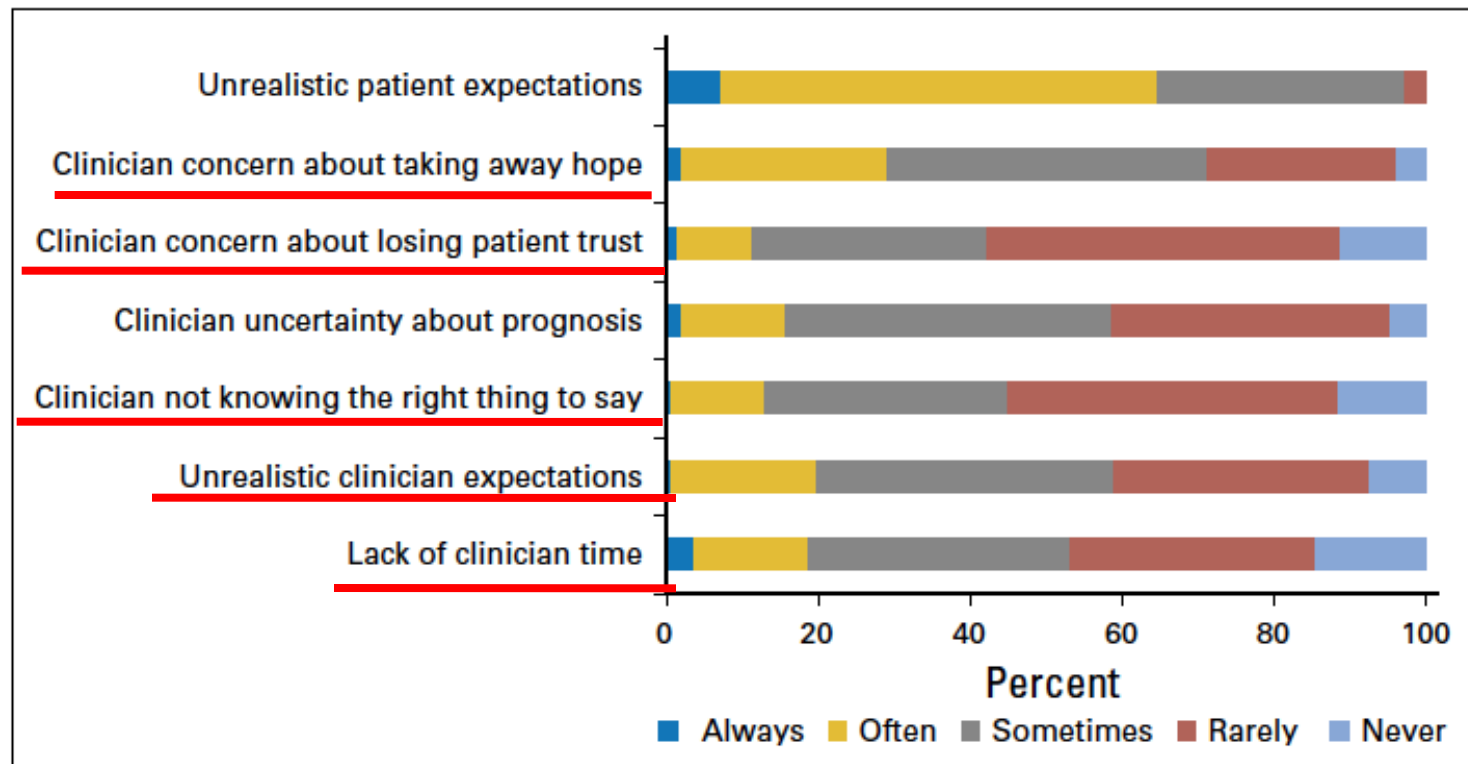


2016

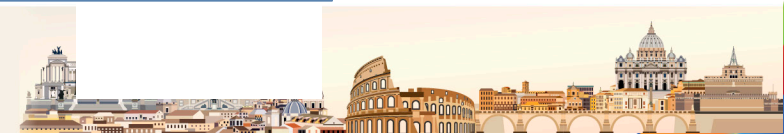
Barriers to Quality End-of-Life Care for Patients With Blood Cancers

Oreofe O. Odejide, Angel M. Cronin, Nolan B. Condron, Sean A. Fletcher, Craig C. Earle, James A. Tulsky, and Gregory A. Abel

E gli ematologi riportano di **NON ATTIVARE UN** percorso di palliazione perchè non vogliono togliere la **Speranza** ai pazienti, perdere la loro **Fiducia**, perchè non sanno come **COMUNICARLO**.



Survey in USA da 334 Emato-Oncologi Nordamericani



Benefici clinici in studi randomizzati e nella pratica clinica
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MISURARE I BISOGNI DEI PAZIENTI: ESAS COME PROs

Edmonton symptom assessment system Global Distress Score and overall survival in acute leukaemia

Monica Morselli,¹ Federico Banchelli,² Eleonora Borelli,^{1,3,4} Stefano Cordella,⁵ Fabio Forghieri,¹ Francesca Bettelli,⁶ Sarah Bigli,⁷ Giuseppe Longo,⁸ Roberto D'Amico,² Carlo Adolfo Porro,^{9,10} Fabio Efficace,¹¹ Eduardo Bruera,¹² Mario Luppi,⁵ Elena Bandieri,¹³ Leonardo Potenza,^{1,6}

BMJ

Morselli M, et al. *BMJ Supportive & Palliative Care* 2022;0:1-3. doi:10.1136/spcare-2022-003838

Figure 1. The Edmonton Symptom Assessment System (ESAS)

		In the last 24 h on average I have felt: Please circle the number that best describes your symptoms:										
	0	1	2	3	4	5	6	7	8	9	10	
No pain	0	1	2	3	4	5	6	7	8	9	10	Worst pain
No fatigue	0	1	2	3	4	5	6	7	8	9	10	Worst fatigue
No nausea	0	1	2	3	4	5	6	7	8	9	10	Worst nausea
No depression	0	1	2	3	4	5	6	7	8	9	10	Worst depression
No anxiety	0	1	2	3	4	5	6	7	8	9	10	Worst anxiety
No drowsiness	0	1	2	3	4	5	6	7	8	9	10	Worst drowsiness
No shortness of breath	0	1	2	3	4	5	6	7	8	9	10	Worst shortness of breath
Best appetite	0	1	2	3	4	5	6	7	8	9	10	Worst appetite
Best feeling of well-being	0	1	2	3	4	5	6	7	8	9	10	Worst feeling of well-being
Best sleep	0	1	2	3	4	5	6	7	8	9	10	Worst sleep

> 60ys

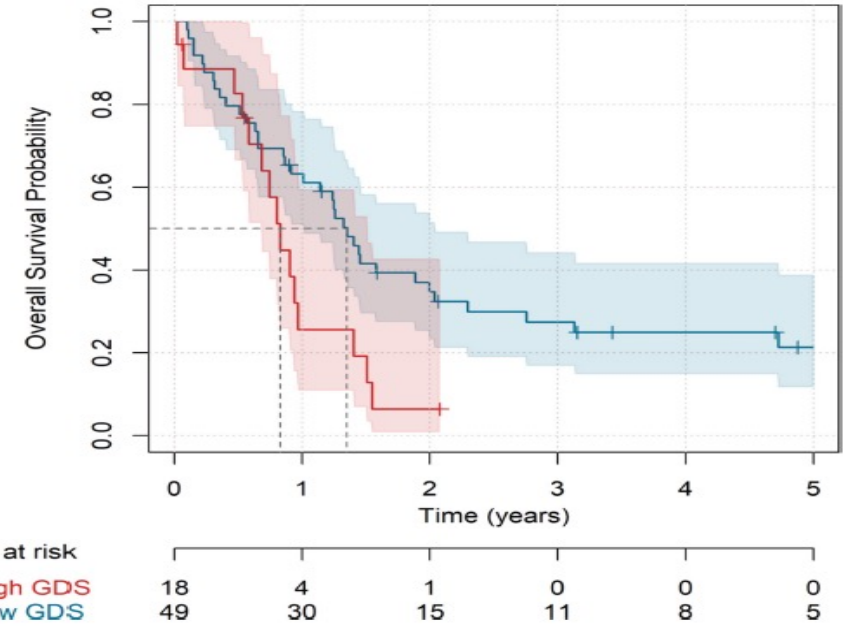


Figure 1 Overall survival curves by Global Distress Score (GDS) score (high vs low).

Global Distress Score-GDS- ESAS 9 items
Tempo di compilazione= 1 minuto



Benefici clinici in studi randomizzati e nella pratica clinica
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Centralità della Comunicazione in EPC: Dolore, Sofferenza, Speranza

The Oncologist®

Symptom Management and Supportive Care

Changes in cancer patients' and caregivers' disease perceptions while receiving early palliative care: a qualitative and quantitative analysis

ELEONORA BORELLI^{1,2,*}, SARAH BIGI³, LEONARDO POTENZA^{1,2,3,*}, SONIA ELIARDO⁴, FABRIZIO ARTIOLI⁵, CLAUDIA MUCCIARINI⁶, LUCA COTTAFAMI⁴, KATIA CAGOSI⁶, GIORGIA RAZZINI⁶, MASSIMILIANO CRUCIANI⁶, ALESSANDRA PIETRAMAGGIORI⁶, VALERIA FANTUZZI⁶, LAURA LOMBARDO⁴, UMBERTO FERRARI⁴, VITTORIO GANFI², FAUSTA LUI^{1,2,*}, OREOFE ODEJIDE⁷, CRISTINA CACCIARI⁸, CARLO ADOLFO PORRO^{9,10,11}, CAMILLA ZIMMERMANN^{8,9,11}, FABIO EFFICACE¹², EDUARDO BRUERA¹³, MARIO LUPPI^{14,15}, ELENA BANDIERI¹⁶

The Oncologist 2021;9999:•• www.TheOncologist

Ricerca multidisciplinare al confine tra le scienze mediche, neuro-cognitive e linguistiche per studiare e migliorare l'evoluzione della comunicazione e relazione con i pazienti ed i loro caregivers.

RESEARCH ARTICLE

Different semantic and affective meaning of the words associated to physical and social pain in cancer patients on early palliative/supportive care and in healthy, pain-free individuals

Eleonora Borelli^{1,2,*}, Sarah Bigi³, Leonardo Potenza^{4,5}, Fabrizio Artioli⁶, Sonia Eliardo⁶, Claudia Mucciarini⁶, Katia Cagossi⁶, Giorgia Razzini⁶, Antonella Pasqualini⁶, Fausta Lui^{1,2}, Fabio Ferlazzo⁷, Massimiliano Cruciani⁶, Eduardo Bruera⁸, Fabio Efficace⁹, Mario Luppi^{4,5,6}, Cristina Cacciari^{1,2,6}, Carlo Adolfo Porro^{1,2,6}, Elena B...

PLOS ONE | <https://doi.org/10.1371/journal.pone.0248755> March 31, 2021

Gratitude among advanced cancer patients and their caregivers: The role of early palliative care

Eleonora Borelli^{1,2,*}, Sarah Bigi³, Leonardo Potenza^{1,3}, Giampiero Porzio^{6,1}, Eduardo Bruera^{10,1}, Fabio Efficace^{9,1}, Mario Luppi^{14,15}, Cristina Cacciari^{1,2,6}, Carlo Adolfo Porro^{1,2,6}, Elena B...

Perceptions of Hope Among Bereaved Caregivers of Cancer Patients Who Received Early Palliative Care: A Content and Lexicographic Analysis

Sarah Bigi^{1,2,*}, Vittorio Ganfi², Eleonora Borelli^{2,3}, Leonardo Potenza^{2,3}, Fabrizio Artioli⁴, Sonia Eliardo⁴, Claudia Mucciarini⁴, Luca Cottafavi⁴, Massimiliano Cruciani⁴, Cristina Cacciari^{5,6}, Oreofe Odejide^{7,1}, Carlo Adolfo Porro^{5,6,1}, Camilla Zimmermann^{8,9,1}, Fabio Efficace^{10,11}, Eduardo Bruera^{11,1}, Mario Luppi^{2,3,*}, Elena Bandieri^{4,1}

Current Oncology

MDPI

Review

Investigating Positive Psychological Well-Being in Early Palliative Care: Values of Hope, Gratitude, and Death Acceptance.

Elena Bandieri¹⁶, Eleonora Borelli^{2,3}, Sarah Bigi³, Claudia Mucciarini⁴, Fabio Gilioli¹, Umberto Ferrari¹, Sonia Eliardo¹, Mario Luppi¹⁴, Leonardo Potenza¹⁴

Words hurt: common and distinct neural substrates underlying nociceptive and semantic processing

Eleonora Borelli¹, Francesca Benuzzi^{2*}, Daniela Elena Bandieri³, Mario Luppi^{1,4}, Cristina Cacciari⁵, Carlo Adolfo Porro² and Fausta Lui²

Early palliative care for solid and blood cancer patients and caregivers: Quantitative and qualitative results of a long-term experience as a case of value-based medicine

Sarah Bigi^{1,2,1}, Eleonora Borelli^{2,1}, Leonardo Potenza^{2,3,1}, Fabio Gilioli⁴, Fabrizio Artioli⁵, Giampiero Porzio⁶, Mario Luppi^{2,3,1}

Caregiver's quality of life in advanced cancer: validation of the construct in a real-life setting of early palliative care

Eleonora Borelli¹, Sarah Bigi², Leonardo Potenza^{1,3}, Fabio Gilioli⁴, Fabio Efficace⁵, Carlo Adolfo Porro^{6,7}, Mario Luppi^{1,3,*} and Elena Bandieri⁸

Dalle linee guida alla qualità di vita e alle cure palliative precoci e simultanee:

come la storia delle leucemie mieloidi acute sta cambiando

Roma, 2 febbraio 2024
Starhotels Metropole



CENTRALITA' della COMUNICAZIONE (e dei CAREGIVERS)

Iniziativa editoriale che raccoglie video interviste di CG di paz onco-ematologici seguiti in EPC, che vuole **approfondire i temi della COMUNICAZIONE**



Dalle linee guida alla qualità di vita e alle cure palliative precoci e simultanee:

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DIFFUSIONE CULTURALE E FORMAZIONE DI POLICYMAKERS, STAKEHOLDERS, CITTADINANZA, ACCADEMIA

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

JAMA Oncology May 2022 Volume 8, Number 5 681

ecancer 2022, 16:1377; www.ecancer.org; DOI: <https://doi.org/10.3332/ecancer.2022.1377>

Figure. Illustrated Metaphor of Late vs Early Palliative Care

A Late palliative care referral



B Early palliative care referral



Camilla Zimmermann,
MD, PhD

Jean Mathews, MD

**EVITARE LO STIGMA DELLE
CURE PALLIATIVE:**

«...referrals are made too late because of misperceptions that palliative care is end-of-life care and palliative care remains synonymous with end-of-life care due to late-referrals...»



FORMAZIONE DI EMATOLOGI, ONCOLOGI, INFERMIERI IN CURE PALLIATIVE PRECOCI



UNIMORE
UNIVERSITÀ DEGLI STUDI DI
MODENA E REGGIO EMILIA

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1° Master Universitario di Secondo Livello

LE CURE PALLIATIVE PRECOCI E SIMULTANEE IN ONCO-EMATOLOGIA E MEDICINA INTERNA: LA CLINICA, LA COMUNICAZIONE E LA QUALITÀ DI VITA

Direttore del Master: prof. Leonardo Potenza (UniMoRe)

Coordinatore Didattico e Organizzativo: dott.ssa Elena Bandieri (Ausl Modena)

Referente: dott.ssa Eleonora Borelli (UniMoRe)

Comitato scientifico: dott.ssa Elena Bandieri, prof. Roberto D'Amico, prof. Massimo Dominici, prof. Fabio Efficace, dott. Fabio Gilioli, prof. Frank Reinhard Heinrich Lohr, dott. Giuseppe Longo, prof. Mario Luppi

Da settembre 2023 a giugno 2025

c/o Centro Oncologico Modenese (COM) e Centro Servizi
Policlinico di Modena - Largo del Pozzo 71, Modena

Dalle linee guida alla qualità di vita e alle cure palliative precoci e simultanee:

come la storia delle leucemie mieloidi acute sta cambiando

Roma, 2 febbraio 2024
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FORMAZIONE DI EMATOLOGI, ONCOLOGI, INFERMIERI IN CURE PALLIATIVE PRECOCI

Haematology and specialist palliative medicine education and training

Table 1 Italian ministerial decrees on education themes and requirements in PC

Italian Ministerial decree 28 March 2013: equivalent specialties to palliative care	Anaesthesia and intensive care, geriatrics, haematology, infectious disease, internal medicine, neurology, oncology, paediatrics, radiotherapy
Italian Ministerial decree 19 May 2020, specialty school of medicine and palliative care. Structural requirements (annex B1): university or affiliated specialist structures that must be present in the training network	Medical oncology, internal medicine, anaesthesia, intensive care and pain therapy, geriatrics, neurology, hospices, domiciliary PC units, ambulatory PC units and hospital consultancy PC services
Italian Ministerial decree 19 May 2020, specialty school of medicine and palliative care. Disciplinary requirements (annex B1): disciplinary scientific sectors considered compulsory and indispensable	Medical oncology, neurology, internal medicine and anaesthesia, intensive care and pain therapy (fundamental teachings)
PC, palliative care.	



Nel mondo scientifico Nordamericano, si persegue da alcuni anni un **percorso di formazione cosiddetto di “dual board certificate” di uno specialista oncologo medico o ematologo clinico, in Cure Palliative.**

The Case for Focused Palliative Care Education in Oncology Training

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LETTER TO THE EDITOR

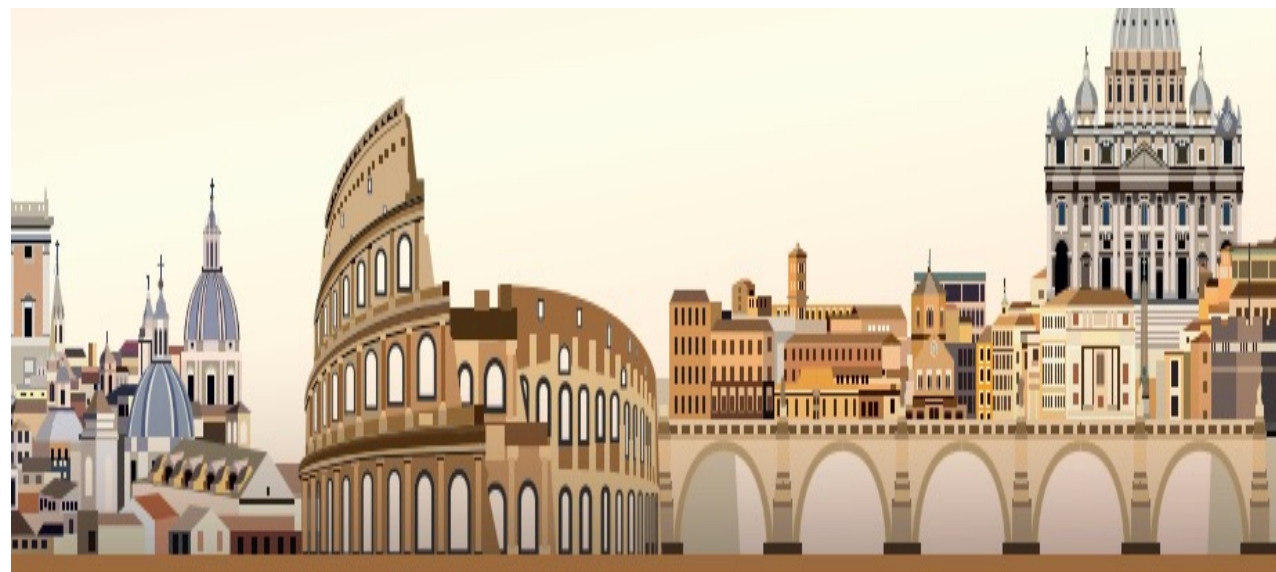
Education of early palliative care specialists among hematologists and oncologists to address patients' rather than physicians' rights

Leonardo Potenza¹ · Mario Luppi¹ · Eleonora Borelli¹ · Sarah Bigi² · Elena Bandieri³



CONCLUSIONI

- Consolidati benefici sono associati all'integrazione di EPC nel Percorso dei Pazienti con Cancro Avanzato. Oltre alle raccomandazioni ASCO, ESMO, AIOM, l'integrazione di EPC in pazienti con LMA, dovrebbe essere ritenuto il nuovo *standard* di cura.
- La soddisfazione dei bisogni di pazienti (IN PRIMIS IL DOLORE) con diverse neoplasia ematologiche, attraverso un modello integrato di EPC, è necessario e urgente.
- Priorità: **Formazione e Ricerca**



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