

Clinical Advances in Myeloma 2020

Improving supportive & palliative care in myeloma services

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@samhja

Disclaimer and Declarations

Disclaimer

I have worked for NIHR, NCRI, NICE and RCP, but the views expressed in this talk are my own.

Declaration

I have no declarations of conflict of interest

All patients and carers have given consent for their pictures

NICE guidelines for management of myeloma and end of life care

NICE guideline NG35 for Myeloma: diagnosis and management (2016)

NICE QS150 for Haematological malignancies (2017)

NICE guideline NG31 for Care of Dying Adults in the Last Days of Life (2015)

NICE QS144 for Care of dying adults in the last days of life (2017)

NICE guideline NG142 for End of life care for adults: service delivery (2019)

How can improve the future of myeloma care?

First – we must know our past, and understand the present

20th century view of cancer care – the WHO resource allocation model

Palliative care was originally defined by the World Health Organisation (WHO) in 1986 as:
“The active total care of patients whose disease is not responsive to curative treatment.”

Diagn

Death

Cu

££



££

End of life care

updated

WHO definition of palliative care (2018)

Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness.

It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.

Evolution of oncology

Original aims

Diagnosis

Cure

Palliation

Modern aims

Prevention

Early and accurate
diagnosis

Cure

Prolonging life

Palliation

Rehabilitation

End of life care

MASCC:

First definition of 'Supportive care' in cancer

“The prevention and management of the
adverse effects of cancer and its treatment.

This includes physical and psychosocial
symptoms and side effects across the entire
continuum of the cancer experience
including the enhancement of rehabilitation
and survivorship.”



Multinational Association for Supportive Care in Cancer

NICE (2004) guidance on “Supportive care” for adults with cancer

‘helps the patient and their family to cope with cancer and treatment of it –

from pre-diagnosis, through the process of diagnosis and treatment, to cure, continuing illness or death and into bereavement.

It helps the patient to maximise the benefits of treatment and to live as well as possible with the effects of the disease.

..given equal priority alongside diagnosis and treatment.’

NICE (2004) Supportive Care Guidance

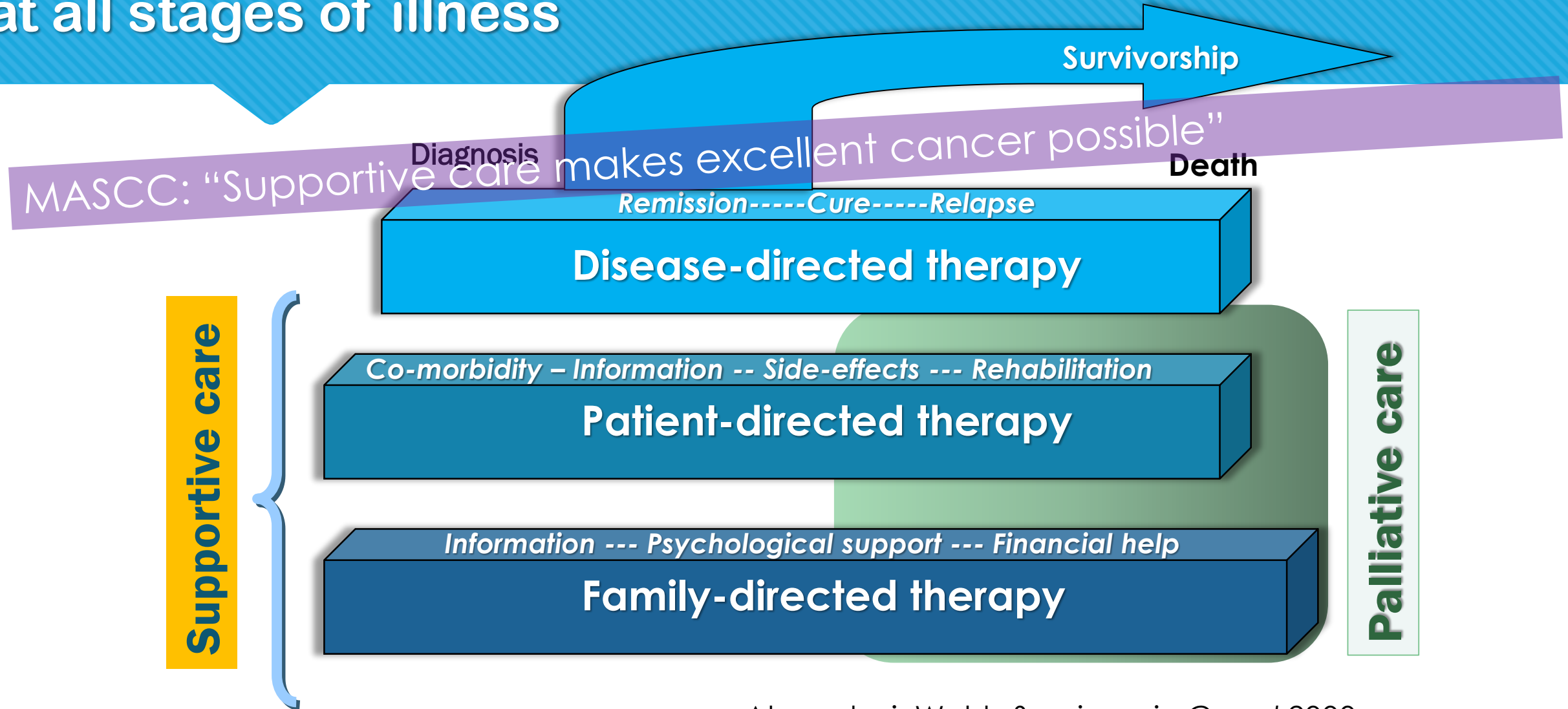
Topic areas

1. Co-ordination of care
2. User involvement in planning, delivering and evaluating services
3. Face-to-face communication
4. Information
5. Psychological support services
6. Social support services
7. Spiritual support services
8. General palliative care services, incorporating end of life care
9. Specialist palliative care services
10. Rehabilitation services
11. Complementary therapies
12. Services for families and carers, incorporating bereavement care
13. Research in supportive and palliative care: current evidence and recommendations for direction and design of future research

Depends on needs – NOT the stage of disease

Sheffield model of supportive care (2000)

Symptoms and psychosocial needs
at all stages of illness



The multiprofessional cancer supportive care 'virtual team'

- Oncology specialist
- Speech therapist
- Palliative care
- Pharmacy
- Social worker



by

therapy

The present

“The future depends on what you do today.”

— Mahatma Gandhi

Current MASCC study groups

- Anti-emetics
- Bone
- Education
- Fatigue
- Geriatrics
- Haemostasis
- Mucositis
- Neurological
- Myelosuppression
- Nutrition and cachexia
- Oral care
- Palliative care
- Paediatrics
- Psychosocial
- Rehab, Survivorship & QoL
- Skin toxicities

Supportive care guidelines generic and disease-specific

bjh guideline

Guidelines for supportive care

John A. Snowden,¹ Sam H. Ahmedzai,² John Ashcroft,³ Shirley D...thy Little
Maclean,¹ Sylvia Feyler,⁸ Guy Pratt⁹ and Jennifer M. Bird¹⁰ On behalf of the Haema
Committee for Standards in Haematology and UK Myeloma Forum

¹Department of Haematology, Sheffield Teaching Hospitals NHS Foundation Trust, Sheffield
University of Sheffield, Sheffield, ³Department of Haematology, Leeds Teaching Hospitals
Haematology, University College Hospital, London, ⁵Department of Haematology, John Rad
Edinburgh, ⁷Department of Clinical Oncology, Freeman Hospital, Newcastle, ⁸Department of
NHS Trust, Huddersfield, ⁹Department of Haematology, Heartlands Hospital, Birmingham
Haematology and Oncology Centre, Bristol, UK

Topics include:

1. Anaemia
2. Haemostasis and thrombosis
3. Infection
4. Pain management
 1. Drugs
 2. Radiotherapy
 3. Other services
5. Peripheral neuropathy
6. Other symptoms (nausea, anorexia, constipation, diarrhoea...)
7. Mucositis
8. BONJ
9. Complementary therapies
10. End of life care
11. Holistic needs assessment

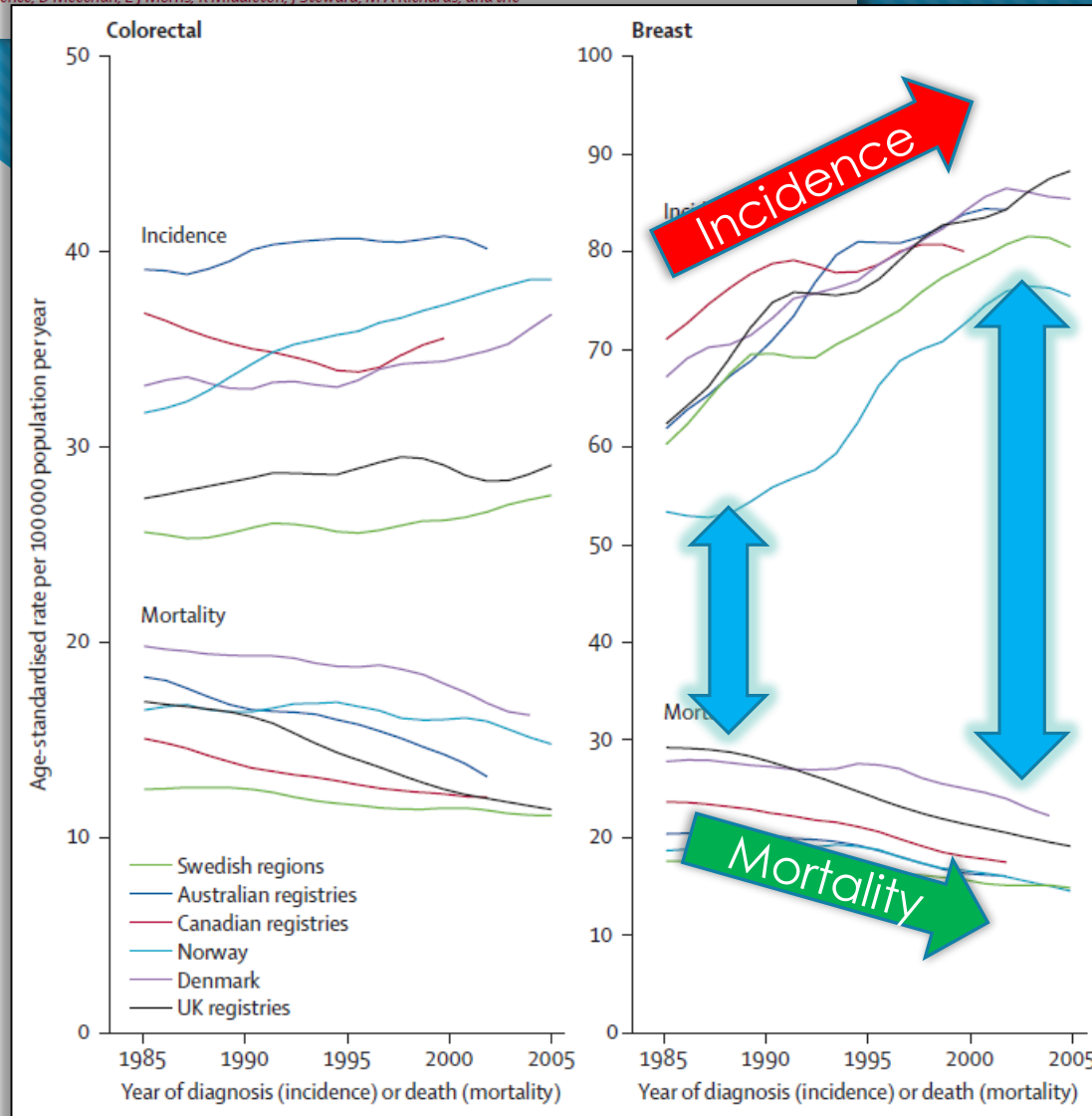
Cancer survival in Australia, Canada, Denmark, Norway, Sweden, and the UK, 1995-2007 (the International Cancer Benchmarking Partnership): an analysis of population-based cancer registry data



Lancet 2011

M P Coleman, D Forman, H Bryant, J Butler, B Rachet, C Maringe, U Nur, E Tracey, M Coory, J Hatcher, CE McGahan, D Turner, L Marrett, M L Gjerstorff, T B Johannesen, J Adolfsson, M Lambe, G Lawrence, D Meehan, E J Morris, R Middleton, J Steward, M A Richards, and the ICBP Module 1 Working Group*

Good news in cancer: Rise of cancer survivorship



Increasing cancer incidence + decreasing mortality = more survivors

Adverse events of targeted therapies

Jean A. Klastersky

Curr Opin Oncol 2014

And the bad news:
new treatments
carry new toxicities

Table 1. Main adverse reactions – % all severity grades and () grades at least 3 and 4

Targeted therapy	Systemic manifestations			Renovascular			Skin and mucosa			Gastrointestinal symptoms			
	Fatigue/ asthenia	Arthralgia/ myalgia	Headache	Hypertension	Proteinuria	↑ Creatinine	Rash and similar	Hand and foot syndrome	Stomatitis/ mucositis	Anorexia	Nausea/ dyspepsia	Vomiting	Diarrhea
Bevacizumab	20 (4)		22 (3)	36 (8)	5 (0)		10 (3)	(3)			6 (0)		5 (2)
Sorafenib	28 (4)	15 (3)	7 (0)	30 (12)	8 (1)		31 (4)	51 (17)	12 (1)	26 (2)	19 (1)	13 (0)	52 (8)
Axitinib	37 (10)	19 (2)	11 (1)	42 (17)	13 (3)		13 (1)	28 (6)	15 (1)	31 (4)	30 (2)	18 (1)	13 (1)
Sunitinib	63 (19)	28 (2)	22 (1)	41 (15)	14 (4)	46 (1)	23 (1)	50 (11)	27 (1)	37 (3)	46 (2)	27 (3)	57 (8)
Pazopanib	55 (11)	30 (3)	23 (3)	46 (16)	18 (4)	32 (1)	18 (1)	29 (6)	14 (1)	37 (1)	45 (2)	28 (2)	63 (9)
Aflibercept	67 (7)	32 (1)	42 (7)	51 (13)	48 (11)					21 (0)	12 (0)	2 (0)	11 (0)
Tivozanib	29 (3)			45 (11)	64 (3)	70 (1)							33 (2)
Cabozantinib	63 (16)			22 (12)				30 (8)	19 (1)	54 (6)	49 (5)	28 (4)	51 (3)
Regorafenib	28 (4)			30 (1)				40 (19)	36 (2)	26 (2)			32 (8)
Vandetanib	24 (6)		26 (0)	32 (9)			45 (4)		56 (8)	26 (1)	29 (1)	14 (1)	30 (2)
Cetuximab	9 (0)	(7)	(7)				18 (12)	7 (0)	6 (0)	5 (0)	6 (0)	6 (0)	30 (0)
Panitumumab	24 (4)						64 (5)	20 (1)		22 (3)	22 (1)	18 (2)	21 (1)
Trastuzumab		(8)	(4)	14 (1)									(6)
Pertuzumab	12 (1)		5 (0)				19 (0)			2 (0)	19 (0)	7 (1)	24 (7)
Lapatinib	19 (0)		9 (0)				29 (1)		2 (0)	10 (1)	28 (0)	18 (0)	48 (7)
Gefitinib	30 (6)						62 (32)	4 (4)	3 (1)	8 (3)	7 (1)		36 (15)
Erlotinib	60 (30)						94 (65)	11 (9)	17 (3)	37 (11)	14 (7)		17 (14)
Crizotinib	27 (2)						9 (0)	8 (0)			55 (1)	47 (1)	60 (0)
Olaparib	48 (6)	12 (0)	18 (0)							18 (0)	68 (2)	31 (2)	23 (2)
Imatinib	35 (1)						31 (0)			32 (0)	28 (1)	16 (3)	31 (4)
Vemurafenib	11 (2)		4 (1)				10 (8)				7 (1)	3 (1)	5 (1)
Vismodegib	36 (4)	68 (4)								23 (3)	29 (11)		22 (1)
Everolimus	33 (3)	20 (2)	19 (1)				36 (1)		56 (8)	29 (1)	29 (1)	14 (1)	30 (2)
Ipilimumab		37 (0)					25 (1)						36 (4)
Lambrolizumab	30 (1)	19 (0)	14 (0)			2 (1)	21 (2)			4 (1)			

What about 'early palliative care'?

The NEW ENGLAND JOURNAL of MEDICINE

August 2010

2010

ORIGINAL ARTICLE

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.,
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What did Temel et al do?

- 151 patients with NSCLC randomised to ‘early palliative care’ (EPC) or ‘standard care’ (SC)
- Massachusetts, Boston
- 107/151 completed 12 weeks follow-up
- All patients on EPC got 1 visit by 12th week
 - EPC average number visits = 4 (range 0-8)
 - SC patients – 10/74 got visit (7=1, 3=2 visits)

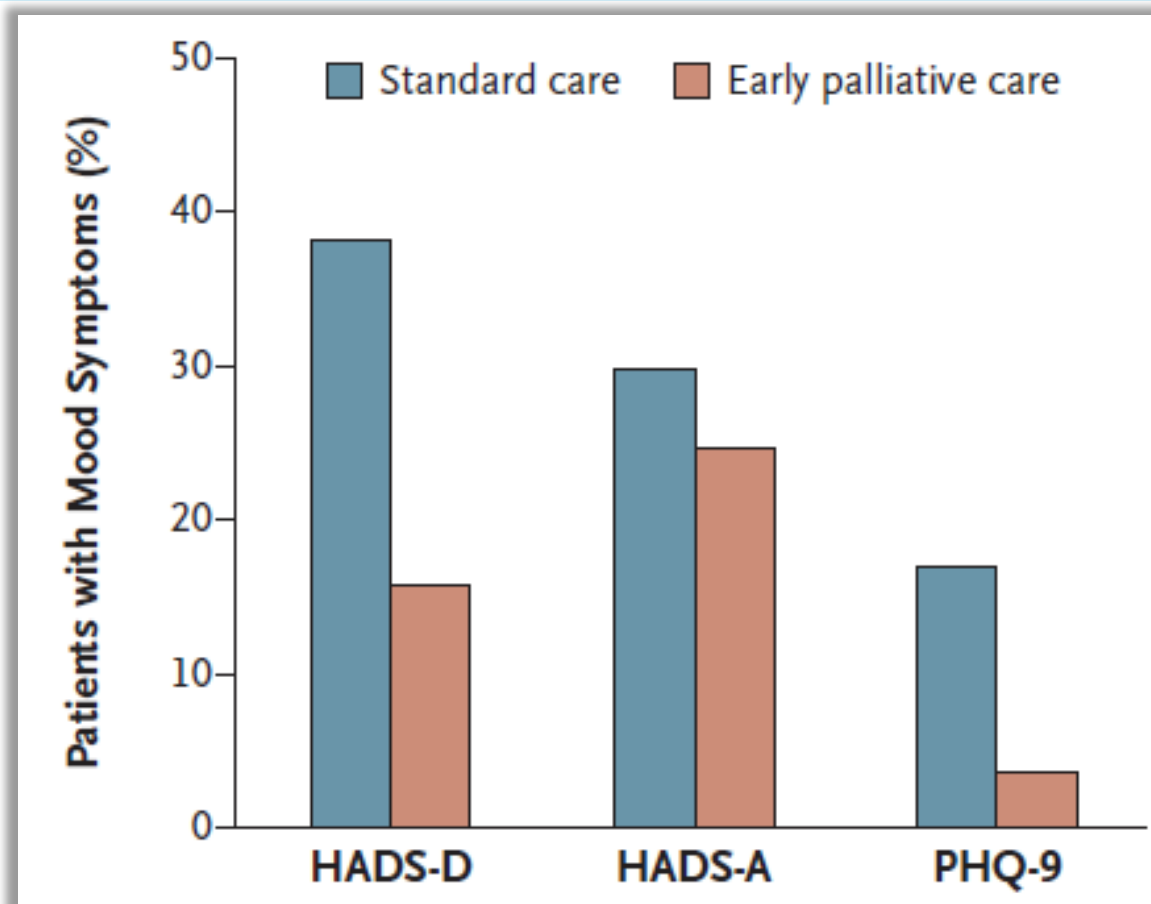
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“Significant”
improvements in all
QOL parameters in
EPC group

Outcomes at 12 weeks



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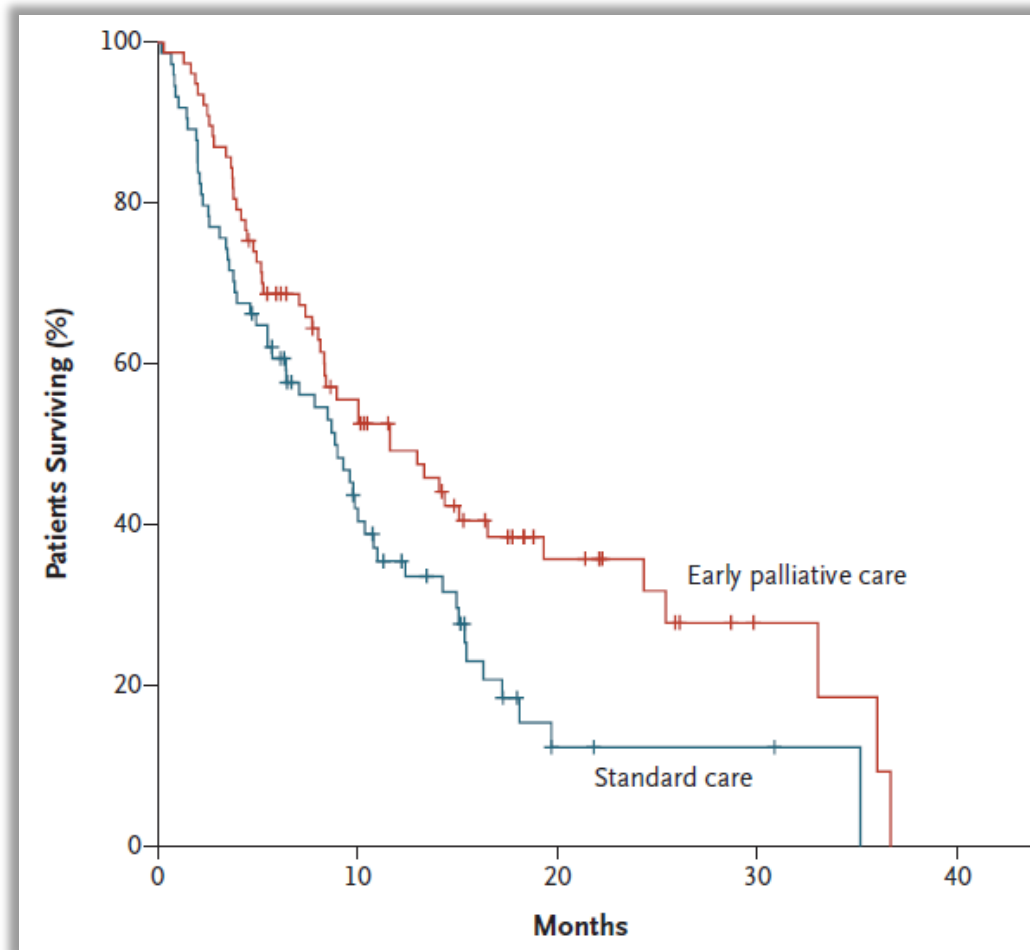
Outcomes at 12 weeks

Significant difference in median survival

- 9.8 months all
- EPC 11.6
- SC 8.9
- P=0.02

Adjusting for age, sex, PS

- HR for death in SC group = 1.70



When does “Early palliative care” start?

- ASCO guideline based on past 7 years of studies of EPC
 - Most in USA
 - Most in cancer
 - Most in ‘advanced’ stage of cancer

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.

'Early palliative care' is not the same as supportive care!

- Why wait till 'advanced disease'?
- Why refer outside of oncology, especially for 'acute' supportive care?
- Skill sets for supportive care are different from palliative care
- 'Palliative' – and 'hospice' – care are emotive terms which distance many patients and families

6 PRINCIPLES OF ESC

1. Earlier involvement of supportive care services.
2. Supportive care teams that work together.
3. A more positive approach to supportive care.
4. Cutting edge and evidence-based practice in supportive and palliative care.
5. Technology to improve communication.
6. Best practice in chemotherapy care.

NHS
England

ENHANCED SUPPORTIVE CARE

Integrating supportive care in oncology
(Phase I: Treatment with palliative intent)



The future

"Prediction is very difficult, especially if it's about the future."

Nils Bohr, Nobel laureate in Physics

SELF
MANAGEMENT

HEALTH AND
WELLBEING

CHOICE AND
CONTROL

INFORMATION
AND ADVICE

SUPPORT

'Living With and Beyond Cancer' (2013)

LIVING WITH AND BEYOND CANCER: TAKING ACTION TO IMPROVE OUTCOMES

Information and
support from point of
diagnosis

Promoting
recovery

Sustaining
recovery

Managing
consequences
of treatment

Supporting
people with
active and
advanced
disease



National Cancer Survivorship Initiative (NCSI):

NHS
NHS Improvement

**WE ARE
MACMILLAN.**
CANCER SUPPORT

DH Department
of Health

Whose responsibility will be the supportive and palliative care of myeloma patients?

1. Haemato-oncology teams
2. Supportive care teams
3. Palliative care services
4. Primary /community care

During anti-cancer treatment?

In remission?

During progressive disease?

Towards end of life?

The future for supportive care

- Location – hospital, or community?
- Specialised education and training for oncologists?
- Workforce – nurses, doctors, AHPs, pharmacists
- Research
- Supportive care guidelines (generic and disease/treatment modality specific)

Importance of families and home care



Supportive AND palliative care:
accompanying the patient on the whole journey –
to remission, recovery, progression or death



Thank you